Functional neurological disorder in acute stroke and mental health services
A mixed methods assessment of experiences, prevalence, associated clinical factors, and treatment.

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Functional neurological disorder in acute stroke and mental health services:

A mixed methods assessment of experiences, prevalence, associated clinical factors, and treatment.

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To Mary and John

Abstract

Functional neurological disorders (FND) present as neurological disease for which no organic cause can be found. These disorders are common, debilitating, and patients can present to a range of medical services. Little is known of the prevalence of patients with functional symptoms presenting to stroke settings, their experience once admitted to stroke wards, the demographic and clinical features of functional motor disorder (FMD) patients treated in psychiatric settings, or their response to psychological treatment. This thesis addresses this paucity of evidence.

A systematic review and meta-analysis found functional stroke patients consistently present to stroke settings, constituting 1.7% (95% CI: 1.3% - 2.2%) of all patients with suspected stroke, with weakness the most commonly presenting functional symptom.

A qualitative study using in-depth interviews with 14 hyper acute stroke clinicians, found participants named a range of potential causes of functional stroke presentations, but many felt unsure in how to discuss a functional diagnosis with patients. In a survey of 120 staff in hyper acute stroke wards in England, 90% of clinicians stated they do not believe there are clear guidelines on how to manage functional patients and 95.8% believed further research is necessary.

A qualitative study involving interviews with 30 patients with functional stroke symptoms at one hyper acute stroke ward found many reported strong negative emotions in response to their admission and while on the ward, many believed they had had a stroke. Two months after discharge, many patients were uncertain about the cause of their admission and 40% experienced residual physical symptoms. Many expressed a desire for a more detailed explanation about the potential cause of their symptoms.

A case-control study of 322 FMD patients found the disorder more commonly affects women, patients more frequently work in social or health care settings, patients often have carers or are themselves carers, and more frequently have comorbid physical and functional disorders when compared to a random sample of psychiatric patients from South London and the Maudsley NHS Trust. We found no association between experience of childhood sexual or physical abuse and an FMD diagnosis; however tentative evidence suggests patients experience precipitating events that could be defined as ‘disruptions to interpersonal relationships’.

Finally, our case-control cognitive behavioural therapy (CBT) study indicates that both FMD patients and patients with organic disease respond to outpatient CBT. Half of the FMD group saw improvements in their physical symptoms, and measures of psychological distress and depression showed significant clinical improvement between first and last treatment sessions. Dropout rates from treatment were comparable between FMD and control patients.

We conclude that functional disorder symptoms occur in multiple medical settings and present to newly established hyper acute stroke wards. A lack of understanding amongst clinicians about the nature of FND coupled with increasing financial pressure on the health service may serve to entrench patients' symptoms, and worsen experiences in medical settings. Within mental health services, FMD appears to have distinct epidemiological characteristics but the fragmentation of neurological and mental health services mean patients are often under-served and lack continuity of care.

List of Abbreviations

ADHD	Attention Deficit Hyperactivity disorder
A&E	Accident and Emergency Department
ANOVA	Analysis of variance
APA	American Psychiatric Association
APSA	Adult physical or sexual abuse
BMI	Body Mass Index
BRC	Biomedical Research Centre
CBT	Cognitive Behavioural Therapy
CFS	Chronic Fatigue Syndrome
CI	Confidence interval
CORE-OM	Clinical Outcomes in Routine Evaluation – Outcome Measure
CMA	Comprehensive Meta-Analysis
CPA	Childhood physical abuse
CRIS	Clinical Records Interactive Search
CSA	Childhood sexual abuse
CT	Computed tomography
CTA	Computed tomography angiography
DLA	Disability Living Allowance
DSM	Diagnostic and Statistical Manual
ECG	Electrocardiogram
EMS	Emergency Medical Services
ePJS	Electronic Patient Journey System
FMD	Functional motor disorder
FND	Functional neurological disorder
GP	General Practitioner
HASU	Hyper Acute Stroke Unit
HIV	Human Immunodeficiency Virus
HoNOS	Health of the Nation Outcome Scales
HoNOS-ABI	Health of the Nation Outcome Scales – Acquired Brain Injury
IAPT	Improving Access to Psychological Therapies
IBS	Irritable Bowel Syndrome
ICD-10	International Statistical Classification of Diseases and Related Health Problems
ID	Participant identifier
ISCO – 08	International Standard Classification of Occupations

IQR	Interquartile range
MRI	Magnetic resonance imaging
MS	Multiple Sclerosis
NA	Not applicable
NES	Non-epileptic seizures
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NK	Not known
OR	Odds ratio
OT	Occupational therapist
PACE	Pacing, graded Activity, and Cognitive behaviour therapy, a randomised Evaluation trial
PCT	Primary Care Trust
PHQ-9	Patient Health Questionnaire
PROSPERO	International prospective register of systematic reviews
RAG	Research and Advisory Group
RCT	Randomised Controlled Trial
R&D	Research & Development
REC	Research Ethics Committee
ROSIER	Recognition of Stroke in the Emergency Room
Rt-PA	Tissue plasminogen activator
TIA	Transient Ischaemic Attack
SD	Standard deviation
SE	Standard error
SES	Socio-economic status
SLaM	South London and the Maudsley
SMR	Standardised mortality ratio
SSNAP	Sentinel Stroke National Audit Programme
SPSS	Statistical Package for the Social Sciences
WHO	World Health Organisation

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Authorship Statement

The research questions and study designs in this thesis were proposed by Prof Antony David and Nicola O'Connell. All data collection, analysis and writing in this thesis was completed by the author.

Thesis Outline

Chapter 1 is a general introduction to functional neurological disorders, outlining its history, prevalence, socio-demographic features, comorbidities, and economic costs. This chapter then outlines the specific aims of this thesis.

Chapter 2 describes a systematic review and meta-analysis investigating the prevalence of stroke mimic patients and patients with unexplained or functional stroke symptoms who present to medical and stroke settings. Potential moderating factors associated with prevalence are explored.

Chapter 3 explores hyper acute stroke staffs' views on diagnosing, treating and referring patients with functional stroke symptoms. The study uses a survey method and semi-structured interviews to explore these topics.

Chapter 4 assesses the views and experiences of functional stroke mimic patients admitted to one hyper acute stroke ward. This study employs semi-structured interviews and the Brief Illness Perception Questionnaire to examine admission experiences, symptomology, illness beliefs, attitudes to clinicians, perceptions of control, and views on the future. Interviews were conducted at patients' bedsides and were repeated two months after patients' discharge.

Chapter 5 describes a case-control study utilising a large anonymous medical database examining the socio-demographics, health and life events of patients with an FMD diagnosis in SLaM NHS Trust. Patients are compared to a control group constituting a random sample of patients from SLaM. The factors associated with an FMD diagnosis are presented and discussed.

Chapter 6 describes a study assessing the clinical outcomes of FMD patients who received CBT from a neuropsychiatry outpatient clinic in South London and the Maudsley NHS Trust. Patients are compared to a control group of patients with organic disorders who received CBT at the same clinic. Physical improvement, dropout rates, and clinical outcomes are examined and compared.

Chapter 7 is a general discussion of the results of this thesis and an attempt to integrate findings within existing epidemiological and psychological models of FND. Recommendations for future service provision and treatment are made.

1.1 Definition

Functional neurological disorder (FND) comprises a spectrum of disorders defined by neurological symptoms for which no organic cause can be found. Symptoms include weakness, motor and movement disorders, dizziness, blackouts, seizures, and disrupted sensory symptoms. Symptoms are incongruous and inconsistent with organic neurological disease.

The disorder has multiple synonyms such as hysteria, conversion, psychogenic, psychosomatic, somatisation, non-organic, and medically unexplained neurological symptoms. This thesis adopts the most recent nomenclature, 'functional neurological disorder', but when discussing the historical development of the disorder in this chapter, we adopt the historical term 'hysteria'[1].

The diagnostic definition of the disorder has changed through the last two centuries. Its copious diagnostic iterations are beyond the scope of this thesis but the current Diagnostic and Statistical Manual of Mental Disorders, version 5 (DSM-5) (American Psychiatric Association, 2013) defines FND as:

- One or more symptoms of altered voluntary motor or sensory function;
- Where physical findings show evidence of incompatibility between the symptom and neurological or medical conditions;
- The symptom is not better explained by another medical or psychological disorder and;
- The symptom causes clinically significant distress or impairment in social, occupational or other areas of functioning.

The International Statistical Classification of Diseases - 10th edition (ICD-10) (WHO, 1992) classifies FND as a dissociative disorder while in the DSM-5 it is defined as a somatoform disorder. Older versions of the DSM required the clinician to identify a potential psychological stressor but such requirements have since been removed as it was deemed both a clinically difficult observation and potentially irrelevant to the diagnosis.

This chapter provides an introduction to FND. It outlines the history and theories of the disorder, its epidemiology, and discusses the aims of this PhD.

[1] Throughout this thesis I will use the term 'FND' and 'FMD'. 'FND' is the more general term, preferred in the neurological and psychiatric literature, referring to the disorder as a whole. 'FMD' refers specifically to 'functional motor disorder'.

1.2 Historical overview

Functional neurological symptoms have a long and varied history, dating back to ancient Egypt, Greece and Rome.

Hippocrates used the term hysteria in the 5th Century BC and claimed the disease related to movement of the uterus (Sigerist, 1951). He distinguished hysteria from epilepsy. The latter he believed was compulsive and the result of brain pathology while hysterical movements originated in abnormal movements caused by uterine problems.

The Romans also believed hysteria was womb-related. Aulus Cornelius Celsus, a Roman encyclopaedist, writing in the first century BC wrote, "S*ometimes it so completely destroys the senses that on occasions the patient falls, as if in epilepsy. This case, however, differs in that the eyes are not turned, nor does froth issue forth, nor are there any convulsions*" (Penso, 2002).

While Celsus associated symptoms with epilepsy, Claudius Galen, a Greek physician and philosopher agreed that while hysteria originated in the womb, there were various symptoms, besides convulsions. His treatments included purges, the administration of various herbs, and marriage (Sigerist, 1951).

1.2.1 Jean-Martin Charcot

The modern history of the disorder began in Paris with the neurologist, Jean-Martin Charcot (1825-1893). Charcot opened a laboratory in the Parisian hospital, the Salpêtrière, and set out to establish what he termed 'a museum of living pathology'. He made detailed observations of nervous diseases. He defined hysteria as a physical disease caused by hereditary deficits or trauma to the central nervous system. He believed hysteria was a brain disorder that could affect men and women and that it was caused by 'functional' rather than structural lesions, a physiological alteration of the nervous system with unknown pathogenesis. He identified a range of symptoms including pain, visual disturbance, motor symptoms, and numbness through to convulsions. He termed convulsions or non-epileptic seizures (NES) '*grande hysteria*' or '*hysteria major*', the classical hysterical sign.

Charcot was at the forefront of modern attempts to classify nervous disease (Bouchara, 2014), a method he applied to hysteria. As the disorder precluded the simple identification and classification of pathogenesis and structural abnormalities, he classified it by its symptom clusters, a tradition that continues today. He also viewed hysteria as separate from malingering or feigning. Given the difficulties in establishing a diagnosis, he photographed patients, fixing their movements or gestures with the intention of helping trainee doctors find

patterns and phases of the disorder, hoping these photographs would form a physiological map of the disorder. He has been described as taking the '*wastepaper basket*' of hysterical symptoms and replacing it with '*a coherent and conceptually elegant array*' (Goldstein, 1987).

Charcot had an idiosyncratic style of treatment and hospital management. He prepared weekly lecture-demonstrations, attracting large audiences. His pupil, the neuropsychiatrist Pierre Janet (1859 – 1947) wrote, '*Everything in his lectures was designed to attract attention and to captivate the audience by means of visual and auditory impressions*' (Guillain, 1959). With a sense of the theatrical, he often imitated the behaviour of patients he was about to present. There is evidence that female patients were 'prepped' by assistants before they appeared and were rewarded for good performance (Ellenberger, 1981).

Figure 1 'A Clinical Lesson at the Salpêtrière' by Pierre Brouillet depicting Charcot demonstrating hypnosis on a female patient

His public platform may have helped bring the disorder to public attention, and there is a suggestion that his fame was responsible for a rise in the rate of hysteria, which rose from a prevalence of 1% in 1841 to 17% in 1883 (North, 2015).

Showalter (1997) and Appignanesi (2008) argue that the socio-political context of France at the time affected Charcot's work. Paris had experienced a surge in anticlerical and anti-establishment sentiment and Charcot's political views are believed to have influenced his approach where he strove to *'reclaim hysteria from religious interpretation…[such as] diabolic possessions or saintly ecstasy'* (Ellenberger, 1994). Two-thirds of Charcot's hysteria patients were working-class women and while he was a practising neurologist, there was huge internal migration from rural to urban French settings. Many of the new arrivals to Paris were women who moved to find work and they often lived alone, on subsistence wages, unsupported by family (Evans, 1991).

The rise in the prevalence of hysteria at the time could represent increased awareness of the disorder, increased help-seeking behaviour within the population, or growth in distress due to the social and economic upheavals of the time. Social and cultural theorists argue however that the fluctuations in prevalence highlight the social malleability of hysteria as a diagnosis and question its validity. Appignanesi (2008) writes, '*doctors and patients collaborated in creating that pattern of illness and discontent'*, arguing that since Charcot's time, the disorder has all but disappeared. Shorter (1992) and Showalter (1997) don't go so far as to claim hysteria has disappeared. Instead they argue that the traditional, '*grande hysterie'* like paralysis and convulsions have vanished, making way for new manifestations such as chronic fatigue syndrome (CFS), with symptoms '*amplified by modern communications and fin de siècle anxiety*' (Showalter, 1997).

The view that the disorder never really existed but instead emerged and grew as a means to define or undermine women, particularly working class women, is common place. While it is possible that the disorder was used as a societal tool, and emerged and was maintained by the specific social, economic, and medical circumstances of the time, the evidence suggests that far from disappearing, its prevalence in fact remained relatively stable through the 20th century. Stone et al. (2008) argue that hysteria did not disappear but due to the fracturing of neurology and psychiatry into separate disciplines, declines in neurologists' interest in non-organic symptoms, continual changes to the name and definitions of 'hysteria', coupled with clinicians' concern regarding misdiagnosis, hysteria cases no longer presented to psychiatrists, giving only the appearance of its disappearance.

Towards the end of his life, Charcot regretted the biological emphasis he had placed in his theory of hysteria. Many of his ideas were dismissed immediately after his death as a new emphasis on traumatic experience developed. While the hereditary basis of his theories have been largely discredited, more recent evidence suggests FND patients often have a family history of psychogenic blindness or NES (Mattoo et al., 2002), and brain imaging studies in functional visual loss show alterations in the visual association cortex (Okuyama et al., 2002).

1.2.2 Pierre Janet

Charcot's student, Pierre Janet (1859-1947) studied and treated hysteria. He conceived hysteria as a disorder in which disturbance in conscious awareness manifests in physical disability (Haule, 1986). He argued that hysteria patients were preoccupied with fixed ideas, and that their "*attention is altogether the most difficult to fix, and that but a few can succeed in directing it*" (Janet, 1907).

Underlying this inability to attend to new sensory information was a process he called 'dissociation', a discontinuation of consciousness. His theory of dissociation involved a 'splitting off' of one part of the nervous system from the central system due to a postulated neurophysiological mechanism (Janet, 1907).

Dissociation also involved the fragmentation of parts of personality into separate compartments; a process he suggested was triggered by extreme stress or emotion. He believed the tendency towards dissociation was an individual predisposition, and symptoms were maintained due to secondary gain for the patient.

He viewed Charcot as placing too strong an emphasis on the physiological underpinnings of the disorder but he was critical of his contemporaries who he believed overstated the disorder's psychological mechanisms. He called for a unification of both approaches, "*Hysteria, they say, is a psychic disease, it is the disease of suggestion…there is some truth in this view, for it brings into relief psychic character of affection; but it is quite insufficient. We should, in my opinion, retain something of the precise method of Charcot, of the search after the determination and the laws of hysteria, and apply it only to psychological facts"* (Janet, 1907).

Modern research supports many of Janet's theories. A number of studies have identified attentional disturbances in patients with NES (Liepert et al., 2011; Pareés et al., 2013). Functional neurological symptoms are classified in the ICD-10 as dissociative and while dissociative mechanisms may be particularly relevant to certain functional disorders such as NES, dissociation is not a process that can in itself account for all functional disorder symptoms (Stone, 2006).

1.2.3 Sigmund Freud

Sigmund Freud (1856 – 1939) was also briefly a student of Charot in 1885. While Charcot had identified and categorised elaborate behaviours, Freud's interest was broader including everyday symptoms, such as headaches, limps, loss of voice and coughs, which he termed '*petite hysterie'*.

He and his colleague Joseph Breuer formulated psychological theories and wrote, "*in what follows, little mention will be made of the brain and none whatever of molecules. Physical processes will be dealt with in the language of psychology; and indeed it cannot possibly be otherwise"* (Breuer & Freud, 1974). They argued that all hysteria had traumatic origins and these traumas were not related to injury or disease. They suggested hysteria resulted from traumatic experiences and memories repressed from consciousness. The memories are highly emotional, stimulating increased brain excitation which is 'converted' into somatic energy. In

their theory, healthy people could get rid of the cerebral excitation associated with emotion, for example through physical movement like shouting, jumping, or crying. If these physical responses were repressed, emotion could persist and become associated and linked to the negative memory.

Freud distinguished between hysterical and psychosomatic symptoms. He believed migraine, headache and stomach pain were psychosomatic but leg paralysis, a classic hysterical symptom, represented the conversion of psychic energy into physical symptoms. In Freud's theory, classic hysterical symptoms held symbolic meaning, with leg paralysis symbolising castration, and blindness representing a wish to look at something forbidden. Dreams for Freud were a way to understand the symbolism of these symptoms.

Their most famous patient, Bertha Pappenheim (1859 – 1936), Anna O., experienced symptoms such as contractions of the right arm and leg, severe cough, mood swings, headaches, sleepwalking, and a loss of voice. They offered hypnosis as a treatment. Under hypnosis, she could provide detailed accounts of the circumstances in which her symptoms had arisen and following hypnosis her symptoms were said to abate. Later they developed psychoanalysis, a talking therapy in which patients told stories, often from dreams or daydreams with the aim of reconstructing the repressed memories through interpretation and free-association.

Freud initially theorised that the repression of childhood sexual abuse from consciousness caused hysteria, writing, '*at the bottom of every case of hysteria there are one or more occurrences of premature sexual experience'*. As the incidence of hysteria grew, he abandoned this view, writing, "*surely such widespread perversions against children are not very probable"* (Freud, 1984). Instead, he favoured a seduction theory that highlighted patients' unconscious sexual and Oedipal fantasies. The change in his causal theory led to heated debate amongst psychoanalysts. The psychoanalyst Jeffrey Masson wrote, '*by shifting the emphasis from an actual world of sadness, misery, and cruelty to an internal stage on which actors performed invented dramas for an invisible audience, Freud began a trend away from the real world, that it seems to me, is at the root of present-day sterility of psychoanalysis*" (Kelly, 1995).

Carson et al. (2016) note that Freud's reversal in thinking should be considered within the context of a broader shift in his views away from defining hysteria as a specific set of symptoms to a disorder that represented global psychological distress. Nonetheless, his Oedipus theory remained and today holds little influence in much modern psychotherapy, viewed both as a misogynistic anachronism and a kind of historical joke. Freud's theories were influential in psychiatry for the first half of the 20th century after which his influence waned.

The essential diagnostic criterion for the identification of psychological stressors at the time of symptom onset was removed from the DSM-5 (APA, 2013). Purely psychological interpretations of the disorder have more recently been challenged on the basis of a lack of evidence for associations between psychological stressors and the disorder (Stone & Edwards, 2011).

1.2.4 World War One

The outbreak of World War One saw a resurgence of interest in hysteria with the return of British soldiers from the front with unexplained limps, loss of voice, headache, pain, mutism, emotional distress and insomnia. Charles Myers (1873 – 1946), a physician and psychologist, encountered British soldiers in France in 1914 and made associations between their symptoms and hysteria (Myers, 1915). Reluctant to employ the term 'hysteria', instead he used 'shell shock'. Initially, Myers had believed the mental distress was a result of soldiers experiencing shells bursting near them but later found these symptoms appeared in soldiers who, "*had never been near an exploding shell, had not been under fire for months, or had never come under fire*" (Myers, 2012). He admitted 'shell shock' was a 'singularly ill-chosen term' and later advocated use of the terms 'concussion', 'nervous shock' or 'war neuroses'.

Gordon Holmes, a neurologist at Queen Square, London, viewed shell shock as the result of weak character and demoted Myers. His views reflected broader public opinion at the time. In the 'Evening Standard', shell shock soldiers were called 'degenerates'. By the 1930s however, such views began to change and psychological symptoms became more accepted as their incidence rose. A psychologist in 1935 wrote, '*In the military hospitals, the study of so-called shell shock revealed that symptoms quite as serious as the well-defined psychoses might arise through simple stress and strain and yet prove quickly curable by psychotherapeutic means*" (Burt, 1977).

After World War One, the huge incidence in shell shock, which saw 80,000 soldiers afflicted, had consequences for theories of hysteria. Perhaps most importantly, the rise of shell shock suggested, as Charcot had argued previously, that hysteria was not a disorder afflicting only women and that sexual trauma and repression alone could not account for its symptoms. Broader accounts of the disorder were needed.

1.2.5 Modern accounts

As noted, through the 1930s to the 1960s, Freudian theories saw a resurgence in popularity in psychological practice, particularly in the United States. By the end of the 1960s however, due to the growth of clinical psychology, rising interest in biological psychiatry, an emphasis on

medical models within psychiatric training, and advances in the philosophy of science (Popper, 1963), psychodynamic theories lost favour. Psychoanalytic theory was robustly criticised for being immune to scientific testing as nothing could, in principle, falsify them. Wittgenstein (1966) likened Freud's theory to a form of mythology whereby psychoanalysis could provide helpful explanations to patients but could not scientifically justify its practices.

Psychiatry and neurology had fractured as disciplines and in 1959, the Archives of Neurology and Psychiatry separated. The new 'American Medical Association Archives of General Psychiatry' stated the decision was a recognition of "*neurology and psychiatry as distinct clinical specialities*" (Grinker, 1959). For most of the second half of the century, both disciplines ignored each other and that schism has mostly continued. Its separation has meant FND patients can be left in a kind of medical no-man's land whereby they may move back and forth between neurologists and psychiatrists with little continuity of care and neither clinician accepting primary clinical responsibility.

Along with this institutional and academic separation, hysteria began to fracture as a unified diagnosis and differing iterations emerged. In the 1960s, Samuel Guze distinguished between a 'conversion reaction' and 'hysteria' writing, '*conversion symptoms are individual symptoms while hysteria is a polysymptomatic disorde*r' (Guze, 1967). He defined hysteria as 'somatisation disorder' or 'Briquet's syndrome' and argued that a diagnosis should be based on a personal history of at least 25 physical symptoms, beginning before the age of 35. In the latest DSM-5 (APA, 2013), somatisation disorder was combined with undifferentiated somatoform disorder and is called 'somatic symptom disorder', no longer requiring a specific number of somatic symptoms for a diagnosis.

Through the 1950s and 1960s, neurologists grew concerned with the issue of misdiagnosis. Eliot Slater, a psychiatrist, argued that misdiagnosis could be as high as 60%, implying that the hysteria diagnosis was often one made in error (Slater, 1965). This view has been robustly refuted. Stone (2016) argues that Slater confused presumed misdiagnosis with incidental diagnoses in his analyses. Nonetheless, Slater's contribution led to a genuine concern that clinicians might misdiagnose FND patients, a concern that continues today (Kanaan, 2009). A neurologist contemporary of Slater, argued that his position was adopted so he could avoid contact with these patients, "*when presented with an essentially curable clinical state that we still cannot banish, we suggest to ourselves that there is no such illness*" (Walshe, 1965).

Other theories that developed through the 20th century that have relevance for current understandings of functional symptoms include illness behaviour theories, and social learning theories.

Illness behaviour theories are sociological accounts of illness which state that different people and groups perceive, evaluate and act upon illness in different ways, and these actions are influenced by cultural and social expectations (Mechanic, 1962). These sociological accounts were the first to help situate illness behaviour within a wider social network while retaining the importance of individual belief and behaviour.

Such theories can be overextended however. This is exemplified in the anthropological work of Mark Zborowski (1969). He classified ethnic responses to pain writing, "*The Irish display a denial of pain, they equate pain with illness and death and so are unwilling to admit to its presence and exhibit some degree of martyrdom. Italians suffer loudly and want everyone to know about the pain they are experiencing. They enjoy the sympathy of secondary gains associated with their verbal reports of pain. Jewish people suffer pain loudly, and family are often closely involved with the suffering. Most are concerned with the meaning of pain*". An anachronism, Zborowski's work seems derived from cultural stereotypes rather than evidence.

Other theories emphasising social context are behavioural learning theories such as classic and operant conditioning which have relevance to the treatment of FND today. Pavlov's (1927) classic conditioning theory and Skinner's (1938) operant conditioning model showed how conditioning can create automatic biological and behavioural responses. In FND, anxiety and panic may come to signal imminent physical symptoms and patients may take steps to avoid situations that believe might heighten such anxiety. These theories are of particular relevance to cognitive behavioural therapy (CBT) treatments of FND where patients are taught how to recognise avoidant behaviours, as well as other therapies like physiotherapy where clinicians adopt positive reinforcement techniques (Nielsen et al., 2014).

Many psychological theories have been posited over the last two centuries, each with useful components. However, like with most psychological disorders, no single framework manages to competently explain the disorder and, as discussed, many have limitations. The current, most commonly held, medical and psychological explanatory model of FND is the 'biopsychosocial' model (Engel, 1977). This model acknowledges the role of biological and psychosocial characteristics but does not assign importance to any single characteristic. One criticism of this theory is that in its attempt to explain everything, instead it explains very little. However, given the continual theoretical and definitional revisions of FND, and the often contentious nature of the disorder itself, a broad, non-prescriptive, agnostic account may be the most appealing and amenable to both patients and clinicians alike.

1.3 Epidemiology

1.3.1 Prevalence

Many of the large population-based epidemiological studies of psychiatric morbidity do not measure the prevalence of functional disorders due to the difficulty and cost involved in excluding neurological disorders on the basis of a questionnaire or interview alone. Studies that do attempt this often rely on patients' recall or GPs' reports which introduce the possibility of recall bias. The expertise of the person making the diagnosis also affects the rate of the disorder. Carson et al. (2000) compared GPs' diagnoses to diagnoses made in neurology clinics. GPs' diagnoses had only slightly better reliability than chance.

Sar et al. (2009) reported a lifetime prevalence rate of conversion disorder of 48.7% in women in the general Turkish population. A one-month prevalence rate of 0.006% was reported in a large survey of the Chinese public using the Structured Clinical Interview for DSM-5 (Phillips et al., 2009). A one-year prevalence rate in the Italian public was estimated at 0.3% (Faravelli et al., 1997). The annual incidence of conversion reactions was 22 cases per 100,000 per year in the US and 11 cases per 100,000 in Iceland (Stefansson et al., 1976). Stefansson et al. used a psychiatric case register; however the other studies used surveys of the general population with no neurological testing, and again are open to biases in recall and reporting.

Within hospital settings, rates are evidently higher. In a retrospective cohort study of frequent attenders in England, Reid et al. (2001) report that 27% of these patients had one or more medically unexplained symptoms. In neurology outpatient settings, the rate varies between 15-35% (Ahmad & Ahmad, 2016; Carson et al., 2000; Fink et al., 2003; Snijders et al., 2004; Stone et al., 2009b; Stone et al., 2010a). These studies assessed patients whose symptoms could not be fully explained by organic disease but when researchers use official diagnoses from the DSM or ICD-10, prevalence rates reduce. One study found 61% of new neurology inpatients had at least one medically unexplained symptom, but 35% fulfilled diagnostic criteria for an ICD-10 somatoform disorder (Fink et al., 2005).

There are limited data available on the prevalence of FND in psychiatric settings. Hafeiz (1980) report a 'hysterical conversion' rate of 7.4% in a psychiatric clinic in Khartoum, Sudan. Liaison psychiatrists in general medicine consistently treat functional disorder patients and referral rates to them vary between 8 - 16% (Clarke & Smith, 1995; Hyphantis et al., 2009; Lipowski & Wolston, 1981). A large study spanning 20 general hospitals found somatoform disorders accounted for 4.1% of referrals to liaison psychiatrists of which FND made up 40%, with the majority of referrals coming from neurology departments (Thomassen et al., 2003).

1.3.2. Socio-demographic factors

Previous research has highlighted the clinical characteristics linked to FND. These include female sex (Ahmad & Ahmad, 2016; Carson et al., 2000; Feinstein et al., 2001; Kim et al., 1999; Lempert et al., 1990), lower socioeconomic status (Deka et al., 2007; Maxion et al., 1989; Stefansson et al., 1976), exposure to physical and sexual abuse in childhood (Nicholson et al., 2016; Roelofs et al., 2005), as well as other traumatic life events such as bereavement or parental rejection during childhood (Binzer & Eisemann, 1998; Creed et al., 2012; Duncan et al., 2006). Patients frequently experience physical precipitating events like head injuries or trauma (Binzer et al., 1997; Pareés et al., 2014). Patients may have been exposed to family or friends with an organic movement disorder (Pellicciari et al., 2014) and neurological disease has been estimated to affect one in ten cases of FND (Stone et al., 2012a).

1.3.3 Comorbidity

Psychological comorbidities are high in FND and consistently higher than rates seen in equivalent organic disorders. Depression and anxiety are consistently reported and the rates vary between 20-40% (Binzer et al., 1997; Carson et al., 2011; Defazio et al., 2017; Lempert et al., 1990; Marsden, 1986; Raskin et al., 1966). It is important to note that depression does not affect all patients. Feinstein et al. (2001) reported rates of depression similar to those seen in healthy controls. Depression can be difficult to ascertain in FND however as patients may be concerned clinicians might dismiss organic illness if they disclose psychological symptoms (Stone et al., 2010b).

Personality disorders are a controversial area in the field. Given their potential lack of clinical utility many clinicians may wish to avoid giving a personality disorder diagnosis altogether. Despite this, in studies that have measured personality disorder, rates are relatively high, ranging between 16-50% (Binzer et al., 1997; Defazio et al., 2017; Folks et al., 1984; Ljungberg, 1957; Scévola et al., 2013).

1.3.4 Cost and disability

The cost of FND to the exchequer is substantial. A study by Barsky et al. (2005) reported patients with somatisation disorder in the US have more primary care, emergency department, and hospital visits, higher inpatient costs, and higher outpatient costs with the total cost, at the national level estimated to be $256 billion a year.

In the UK, patients with FND, admitted to a district general hospital, stay for an average of 17 days and have up to eleven scans during that period. The average cost to the hospital over two years was £13,288 (Adjei & Coebergh, 2014). In Ireland, the economic cost of NES is estimated

to be €5429 per patient and the national annual cost of these conditions to the Irish exchequer is €27 million annually (Magee et al., 2014). A systematic review on the economics of FND reported significant expenditure, with excess costs ranging from $430 to $5300 per patient (Konnopka et al., 2012).

The cost to the individual is also high with high levels of disability experienced by patients and has been reported to be comparable with severe neurological disorders. Many patients remain chronically ill after a diagnosis (Feinstein et al., 2001; Williams et al., 1995), leading to continued disability at work and home. Carson et al. (2011) report that 50% of patients with unexplained symptoms in a neurology outpatient clinic were unemployed and 20% received income support or unemployment benefits, and 27% received incapacity benefits. The receipt of benefits was significantly higher in these patients than in patients with organic neurological disease. The burden of the disorder is therefore high, both for health care systems and patients themselves.

In conclusion, FND is a disorder with a rich and varied history, and perhaps the first modern psychological syndrome. Theoretical understanding and scientific accounts of the disorder have suffered due to the separation of neurology and psychiatry as disciplines and modern dualistic conceptualisations of the mind and body. Despite this, it is a disorder that exists in the modern world, with a high cost and disease burden. It has its own socio-demographic profile, albeit one that may vary depending on the settings and the techniques used to identify it.

1.4 Aims of thesis

Our historical description of FND, through its various nosological forms, highlights the changes in medical and psychological accounts of the disorder and its relative stability as a reliable diagnosis. Unexplained physical symptoms are common and they occur in every known medical setting from dentistry through to cardiology and gastroenterology (Nimnuan et al., 2001). While these patients might not necessarily qualify for an FND diagnosis, their presence suggests that regardless of speciality, physicians routinely encounter patients with unexplained or functional symptoms.

Medicine, in response to advances in medical science and technology has become more specialised and, with exceptions like primary care and general medicine, most physicians and surgeons are trained in only some kinds of medical care. In 1960 for instance there were 18 speciality medical boards in the US, and by 2011 there were 158 (Detsky et al., 2012).

The development of specialised services and accompanying medical subspecialties along with a proliferation of advanced diagnostic tools mean new forms of FND presentations may appear

in newly developed services. Recent examples of this include the presentation of patients with medically unexplained visual loss to a specialist neuro-ophthalmology clinic (O'Leary et al., 2016) and a study which reported that 84% of patients who received an emergency lumbar magnetic resonance imaging (MRI) scan for suspected cauda equine syndrome did not have the disorder. Scan-negative patients were more likely to be female and younger, and a proportion went on to receive psychiatric follow-up (Gibson et al., 2017).

Where new medical or neurological services are set up to accommodate the treatment of specific physical disorders or to improve access to new diagnostic techniques, it is likely that FND patients will form part of presentations to these services. One question related to this is whether the patients with unexplained neurological symptoms attending new types of services have similar symptoms to FND patients attending other services. Are their symptoms transitory for instance or do they follow a chronic course of the illness?

A previously unexplored medical specialty in which new manifestations of FND may present is to hyper acute stroke care. Hyper acute stroke units (HASUs) were established in London in 2010 in a bid to increase the application of stroke medicine, reduce admission times and mortality. Inevitably, FND patients enter the hyper acute stroke pathway. Stroke medicine routinely accounts for the rate of patients presenting to stroke services who have symptoms that mimic stroke, ('stroke mimics') but often give little detail regarding who these patients are and where they go after their admission. Apart from one previous paper by Garagalas et al. (2016), no research has specifically focused on the proportion of stroke mimics with a functional explanation for their symptoms. Anecdotally, clinicians were at a loss as to how to treat these patients as there are no guidelines on the treatment or referral of FND patients from HASUs. Chapter Two of this thesis aims to establish the prevalence rates of FND patients' presentations to stroke settings and to investigate the socio-demographic and clinical factors associated with these presentations.

Hyper acute stroke care is a relatively recent phenomenon. Chapter Three aims to investigate and describe the attitudes, opinions and experiences of hyper acute stroke clinicians towards FND patients in stroke settings through the use of a large survey and a series of semi-structured interviews.

While Freud was the first to emphasise the importance of listening to the stories and experiences of patients, surprisingly little research has focussed on FND patients' voices or views, particularly regarding their own treatment. Chapter Four aims to investigate the attitudes and experiences of patients with unexplained stroke symptoms admitted to a HASU in an attempt to identify the emotional and psychological effects of such admissions and the

role that patients' illness perceptions play in the maintenance of symptoms. This study uses semi-structured interviews and two-month follow-up interviews as well as the Brief Illness Perception Questionnaire.

Pervasive throughout FND research is a lack of large sample sizes. The predominance of evidence comes from medical and neurology settings, often in the form of case studies. While there is some evidence to suggest that most FND patients consider that they have a neurological disease (Stone et al., 2004a), a proportion of these patients will be referred to psychiatric services. Little is known about who these patients are, whether they differ to other patients receiving psychiatric interventions, and how they respond to treatment.

Chapter Five attempts to address the lack of statistical power in previous research by utilising a large retrospective database to assess the presentation of patients with FMD. We first established a cohort of patients with FMD and examined their socio-demographic, and health factors, as well as their life experiences, and clinical outcomes. The characteristics of this group were compared to a random sample of psychiatric patients derived from the same database, which allowed comparisons of clinical factors and the identification of risk factors in FMD presentations.

The final study addresses the lack of existing research on the effectiveness of psychological treatments for FMD. Using the same database, Chapter Six assesses the effectiveness of CBT for FMD patients delivered in a neuropsychiatry outpatient clinic. The study aims to investigate the outcomes of FMD patients who received CBT treatment compared to patients with organic disorders treated in the same clinic. We also sought to compare CBT-uptake rates, dropout rates, the rate of physical symptom improvements and the change in acceptance of psychological explanations between the start and end of therapy, and clinical outcomes.

Chapter Seven describes findings within the context of existing literature, compares findings from across the five studies and makes recommendations for future service provision and treatment.

Chapter Two: A systematic review and meta-analysis of the prevalence of stroke mimics and functional stroke mimics across differing medical settings

2.1 Introduction

Stroke is the world's third most common cause of death after ischaemic heart disease and cancer (Warlow, 2003). In 2007, there were 125,945 reported strokes across England (Townsend, 2012). Of stroke patients, approximately 40,000 will die of the disease (Mackay, 2004). In 1990, stroke accounted for 3% of the world's disability burden (Warlow, 2003) and as the proportion of older adults across the globe increases, the rapid and accurate diagnosis of stroke has become increasingly important (Royal College of Physicians Sentinel Stroke National Audit Programme, 2014; Townsend, 2012).

Given its worldwide burden, continual attempts are made to improve stroke detection and outcomes. This has led to an emphasis on rapid hospital admission and treatment. There has been a drive to both improve services and increase public awareness of symptoms. This has meant, inevitably, that patients, whose symptoms 'mimic' stroke, end up in stroke services. Many medical diseases and disorders can mimic stroke like headache, brain tumours, seizures, infection, and vertigo. A proportion of stroke mimic patients have a functional disorder and, potentially, a psychological explanation for their presentation.

In this chapter, the term 'medical mimics' will be used to refer to differential stroke diagnoses which have a medical etiology, while 'functional mimics' will refer to patients with functional, psychological, or medically unexplained symptoms.

This study is a systematic review and meta-analysis assessing the proportion of stroke mimic and functional mimic patients presenting with suspected stroke. This introduction outlines the diagnosis and treatment of stroke, the restructuring of stroke care in London, public health campaigns to increase awareness of stroke, existing literature on the demographic and clinical features of stroke mimic and functional stroke patients, before outlining the aims of this study.

2.1.1 Stroke pathway

2.1.1.1 Stroke definition

Stroke is defined as the "rapid onset of focal or global cerebral deficit, lasting more than 24 hours or leading to death, with no apparent cause other than a vascular one" (WHO, 1992). Stroke symptoms can include paralysis on one side of the body, sudden loss or blurring of vision, numbness, dizziness, confusion, difficulty understanding words, balance problems, difficulty swallowing, sudden severe headache, and loss of consciousness.

There are two main types of stroke: ischaemic, caused by thrombus, and haemorrhagic.

Haemorrhagic strokes account for 20% of all strokes and are associated with a higher risk of mortality compared to ischaemic strokes (Royal College of Physicians, 2014).

There are many stroke risk factors including older age, cigarette smoking, diabetes, and obesity (Prospective Studies Collaboration, 2002), a history of atrial fibrillation, hypertension, diabetes, coronary heart disease, and hyperlipidemia (Merino et al., 2013).

2.1.1.2 Stroke diagnosis and treatment

The stroke pathway has three distinct phases, the emergency setting, the acute phase, and rehabilitation.

Paramedics are usually the first clinicians to assess stroke, attending up to 70% of patients eventually admitted to hospital (Lacy, 2001). They have an average diagnostic accuracy of between 80-95%, but often don't correctly identify stroke mimic patients (Kothari et al., 1995). The Los Angeles Prehospital Stroke Screen, the Cincinnati Prehospital Stroke Scale, the Melbourne Ambulance Stroke Screen (Kidwell, 2000) and the Face Arm Speech Test (FAST) in the UK are some of the screening measures developed to improve paramedics' identification of stroke, and to help standardise its evaluation.

The FAST test is used by the London Ambulance Service. It assesses facial droop, arm drift and speech changes or slurring of speech, emphasising the importance of time. The Recognition of Stroke in the Emergency Room (ROSIER) scale (Nor et al., 2005) was developed for use in the emergency room but is also currently being trialed by ambulance services in North East London in attempts to improve the diagnosis of stroke.

Once relayed to hospital, brain imaging is the most common method of diagnosis. Computed tomography (CT) is the gold standard diagnostic tool for the diagnosis of acute haemorrhage within the first week of stroke onset (Warlow, 2003). A normal CT scan does not immediately imply stroke-free status. Even though CT scans can detect haemorrhagic strokes, they only have 40% sensitivity for the confirmation of acute ischaemic stroke (Mullins et al., 2002).

Brain MRI with diffusion weighted imaging is highly sensitive and specific for the detection of early cerebral ischaemic stroke (van Everdingen, 1998) and is more sensitive than a CT scan (Brazzelli, 2009). MRI scans are costly however and take time to administer (Vymazal et al., 2012). In addition, they may not identify an acute haemorrhage within the first hours of onset as a hematoma can be mistaken for a tumour (Warlow, 2003). They are often ordered for patients with more complex symptoms where the potential location of the stroke is unknown. The sensitivity of both CT and MRI techniques decreases as time passes. A combination of clinical examination with imaging is therefore the gold standard diagnosis of stroke.

Stroke treatments include surgical interventions, reversal of anticoagulation and most commonly, the administration of the clot-busting medication, thrombolysis. Like the receipt of a diagnosis, these treatments are time-critical. Thrombolysis should ideally be given within 3 hours, but not after four and a half hours of symptom onset (Wardlaw et al., 2014).

The detection of stroke is not straightforward. Fast diagnosis and treatment is paramount to survival and future outcomes. The risk threshold for a clinician to admit and treat a potential stroke will generally be low, and as a result, patients with differential diagnoses can enter the stroke system.

2.1.1.3 Restructuring stroke care in London

Prior to 2010, London's stroke system was underperforming in comparison to the rest of the UK. The system included 30 local hospitals providing care for acute stroke and there was wide variation in the number of patients treated across London. While most strokes occur in the outskirts of the city where more elderly and poorer populations live, at the time, most stroke beds were located within inner London.

In 2006, a report recommended greater specialised acute stroke care through dedicated, high-volume, specialised stroke units providing care to patients in the 72 hours after stroke onset (Healthcare for London, 2007). The overall aim was to provide rapid assessment and treatment for stroke patients in London, regardless of their location within the city, or the time of stroke onset. In July 2010, services were restructured and eight HASUs were established.

The change in stroke care led to improvements in stroke patients' outcomes. The thrombolysis rate in 2013 in London increased to 17% compared to an English average of 12% (Royal College of Physicians, 2014). The stroke survival rate also increased from 87.2% to 88.7% (Hunter et al., 2013) and this decline in mortality was sustained 90 days after discharge. Additionally, the length of hospital stay reduced (Morris et al., 2014). The HASU model's success has led to its uptake in urban regions outside London including Manchester, Newcastle, and Southampton.

While the restructuring of services has brought positive change for stroke patients, functional patients also enter the hyper-specialised pathway but are often promptly discharged from services and are provided with little support or aftercare.

2.1.1.4 Public awareness campaigns

In conjunction with the re-organisation of stroke services, there has been a global drive to improve the public's awareness of the signs of stroke. A public health campaign run by the Department of Health between 2009 and 2012 advertised the FAST test directly to the public

through national media campaigns, community stroke screening events and patient education[2]. Figure 2 displays an example of a poster used by the campaign.

Figure 2 Campaign poster from the UK's Department of Health (2007) public awareness of stroke campaign

Following the campaign, a time trend analysis showed increased public interest in stroke-related information through access to resources like websites, webpage views, and calls to stroke helplines (Flynn, 2014). There were increased stroke-related emergency admissions and increased thrombolysis administration. Mass media campaigns targeting the public's awareness of stroke in Ireland in 2010 demonstrated a significant increase in the attendance to emergency departments after the campaign (Mellon, 2013), although a study in the Czech Republic demonstrated less success in the improvement of public awareness of stroke (Mikulik, 2011).

Publicly available data from 'Google Trends' shows searches for terms like 'stroke' have increased over the past decade on the search engine[3]. Figure 3 shows (A) a steady increase in the proportion of UK Google searches for the terms 'FAST' and 'stroke' from January 2008 to January 2017 and (B) an increase in the proportion of worldwide searches for the term 'stroke' in the same time period.

[2] Information available at: http://www.nhs.uk/Actfast/Pages/stroke.aspx
[3] Information available at: https://trends.google.co.uk/trends/explore?date=2008-01-01%202017-01-01&geo=GB&q=FAST%20stroke and https://trends.google.co.uk/trends/explore?date=2008-01-01%202017-01-01&q=stroke

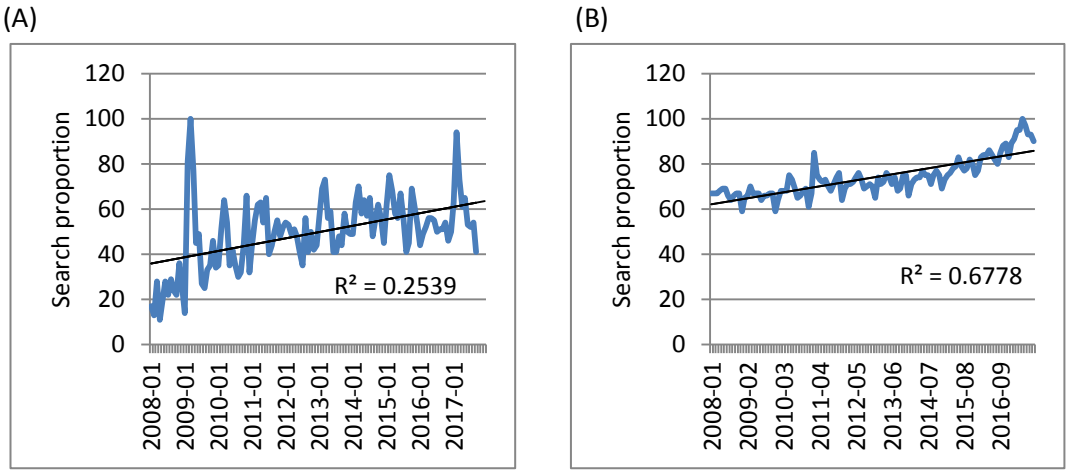

Figure 3 Increases in internet interest in the signs of stroke. Graph A shows increases in frequency of UK Google searches for the terms 'FAST' and 'stroke' between 2008-2017, Graph B shows increases in worldwide Google searches for the term 'stroke' over the same period

It is possible that these trends reflect an increased interest in medical terms and symptoms generally or increased access to the internet, rather than public knowledge or interest in stroke specifically. The results may also reflect increases in the global burden of diseases related to population ageing, however Google searches for Alzheimer's disease, also a disease affected by ageing populations, do not show the same positive trend.

It is likely that these public awareness campaigns have contributed, at least partly, to knowledge and interest in the signs and symptoms of stroke and this has led to increased help-seeking from stroke services. This, in turn, may have led to higher rates of false positive admissions to stroke settings where people misinterpret physical symptoms as stroke and seek medical intervention. While the re-organisation of services has helped improve stroke outcomes, larger numbers of stroke mimic patients may be admitted to services (Kwan et al., 2004).

2.1.2 Stroke mimics

Stroke mimic patients display stroke-like symptoms that are not explained by stroke. A systematic review by Gibson and Whiteley (2013) reported that stroke mimics make up 20-25% of suspected stroke diagnoses and they present to primary care, emergency, secondary and acute settings, with the highest rate of stroke mimics found in ambulatory settings. They report that the most frequent stroke mimic diagnosis was seizure (19.6%), followed by syncope (12.2%). Functional patients made up 7.4% of stroke mimic patients.

Diagnosing and treating stroke mimic patients is costly. In the United States, the excess direct hospital cost is $15 million per year, with an average cost of $5,400 per admission (Goyal, 2015).

Some studies have attempted to identify stroke mimics' distinguishing features. Current data suggests stroke mimic patients are more likely to be female, African American rather than Caucasian, and more likely to arrive at the emergency department in a private vehicle than ambulance (Merino et al., 2013). Stroke mimic patients are also likely to be younger than stroke patients. Vroomen et al. (2008) reported that of patients aged under-50, the stroke mimic rate was 21%, but amongst patients aged over-50, the stroke mimic rate was much lower at 3%.

Stroke mimics have less severe deficits at baseline and have a shorter symptom onset-to-treatment time compared to stroke patients (Chen et al., 2011). Furthermore, they are more likely to have a history of cognitive impairment and to present with aphasia, but are less likely to have a history of hypertension or to display facial palsy, sensory loss or visuo-spatial neglect (Forster et al., 2012). Stroke mimics were less likely to have experienced a loss of consciousness or seizure when their symptoms began (Hand et al., 2006) and they have lower ROSIER scores than stroke patients (Edwards et al., 2015).

The current protocol for the management of stroke mimic patients in HASUs is their repatriation to an 'appropriate medical setting within 24 hours of the non-stroke diagnosis being made' or direct discharge home (NHS London Strategic Clinical Networks, 2014). There are no specific guidelines on functional mimic patients. Patients with a non-stroke diagnosis and a non-medical explanation for symptoms who are admitted into a stroke pathway will likely be discharged quickly. Problems may further arise as the planning document for the restructuring of stroke services anticipated a stroke mimic rate to HASUs of 15%, a potential underestimate (Healthcare for London, 2009), substantially less than the 24% rate reported in Gibson and Whiteley's (2013) paper.

2.1.2.1 Functional stroke mimic patients

Gibson and Whiteley's (2013) systematic review was the first to provide an aggregated figure of the proportion of stroke mimics who have a functional disorder. As mentioned, they report that 7.4% of stroke mimic patients have FND, and a further 5% have 'non-specified' symptoms.

From individual studies, the rate of functional stroke patients has been reported to be as high as 38 - 41% (Gargalas et al., 2015; Scott & Silbergleit, 2003; Vroomen et al., 2008). These high rates might be partly explained by the fact Gargalas et al. (2015) specifically aimed to assess the stroke mimic rate, making use of neuropsychiatry experts to make the functional diagnosis, while Vroomen et al. (2008) listed no 'other' or miscellaneous category.

While Gibson and Whiteley's (2013) systematic review provides information on the overall rate

of functional patients' attendance at differing medical services, they included only prospective studies and reported only one moderating factor, the influence of the medical setting on the stroke mimic rate.

Little is known about the demographic or clinical features of FND patients who present to stroke settings, with most information coming from case series. Gargalas et al. (2015) examined the distinguishing features of functional mimic patients. Functional patients were younger than both medical stroke mimics and stroke patients, were most likely to present with isolated weakness followed by slurred speech and compared to medical mimics were more likely to have symptoms of depression, back pain, migraine, and asthma. Functional mimic patients were more likely to be discharged directly home compared to medical mimics and stroke patients. After follow-up, they reported that of those patients for whom data were available, 59% of patients had been referred to another service after their admission, and this was most frequently to the 'Improving Access to Psychological Therapies' (IAPT) service.

2.1.3 Study aim

The care pathway for stroke patients is established and effective but there is little clinical or research interest in the treatment of patients with functional disorders who are admitted into the stroke pathway. With the exception of Gargalas et al.'s (2015) study, little is known about these patients, their prevalence, or their demographic features.

Receiving invasive or unwarranted treatment may have harmful physical and psychological effects. Stroke mimic and functional patients may face negative consequences due to delays in receiving the correct diagnosis and treatment. Functional disorder patients have been treated with thrombolysis, and while the medication appears safe, the lack of guidelines on the care or appropriate referral of these patients within stroke centres is conspicuous.

This chapter outlines a study on the prevalence of functional patients who are referred to stroke services. This systematic review and meta-analysis aims to:

I. Review the literature on stroke mimic patients and functional stroke mimic patients;
II. Establish the demographic and symptom profiles of functional patients;
III. Determine the proportion of patients presenting to acute emergency, medical or stroke services who had a stroke mimic diagnosis;
IV. Determine the proportion of stroke mimics who have a functional disorder diagnosis;
V. Assess the effect of moderating factors on the rate of stroke mimic and functional diagnoses including the diagnosis site, study design, exclusion criteria, countries' economic status, treatment, year of publication, aim of the study and quality scores.

2.2 Methods

This review was registered with the National Institute for Health Research's International Prospective Register of Systematic Reviews (PROSPERO) on the 31st October 2014[4].

This study aimed to review all published reports of the prevalence and incidence of stroke mimic patients across all clinical settings.

A literature search was performed in two stages. The first search took place in October 2014 and a second search, using more comprehensive search criterion, began in June 2015 and was completed in April 2016.

2.2.1 First literature search

The first literature search was performed using the following databases: CINAHL, PubMed, OvidSP and Google Scholar. The search term "stroke mimic*" was used. Grey literature and conference proceedings were excluded.

The first database searched was CINAHL. CINAHL is an index of English-language journal articles about nursing and biomedicine. This search began on 21st October 2014 and returned 62 papers. After a review of abstracts, 27 papers were chosen for further review on the 21st October 2014.

OvidSP was searched on 22nd October 2014. OvidSP is a gateway programme for the databases Embase (searched from 1980 to October Week 2, 2014), PsychINFO (searched from 1806 to October Week 3, 2014) and Ovid Medline (searched from 1946 to October Week 2, 2014). The search term produced 397 papers. On 21st November 2014, 144 papers were chosen which met the inclusion criteria.

PubMed was searched on 27th November 2014. PubMed accesses the MEDLINE database which comprises abstracts on life-sciences and biomedical topics. The search resulted in 173 papers. A total of 44 papers were chosen for inclusion on 27th November 2014.

The final database searched was Google Scholar. Google Scholar includes most peer-reviewed online journals of Europe and America's largest publishers. The search engine does not publish the exact size of the search. Of 200 relevant search results reviewed, 29 were chosen for inclusion on 28th November 2014.

The total number of papers at this stage of the review was 244. The full version of each study

[4] The study's code is: PROSPERO 2014:CRD42014014632.
http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42014014632

was read and reviewed and 210 papers were excluded based on the inclusion criteria. Figure 4 shows a flow chart displaying the first search strategy as well as the reasons for papers' exclusion.

2.2.2 Second literature search

To ensure a comprehensive search, a second search began in June 2015.

The search strategy used here was: [(Suspect* adj (((Cerebr* or intracerebral or brain) adj (ischem* or haemorrhage* or hemorrhage or bleed* or infarct*)) or (Stroke or brain attack or cerebrovascular attack or cva))).tw.] or [((Mimic* or differential or misdiagnos*) adj3 (((Cerebr* or intracerebral or brain) adj (isch?em* or haemorrhage* or hemorrhage or > bleed* or infarct*)) or (Stroke or brain attack or cerebrovascular attack or cva))).tw.] or [*stroke/di]. The search results were limited to humans.

This search utilized OvidSP searching the databases PsychINFO, Embase and Ovid Medline. The search returned a total of 11,915 papers. The title and abstracts of these papers were read and 311 were chosen for more in-depth reading. 109 of these papers were then chosen as potential papers for inclusion. 53 papers were then chosen and 56 excluded.

The total number of papers included from both search one and search two in this study is 87.

Figure 4 displays the study's search strategy and reasons for exclusions at each stage.

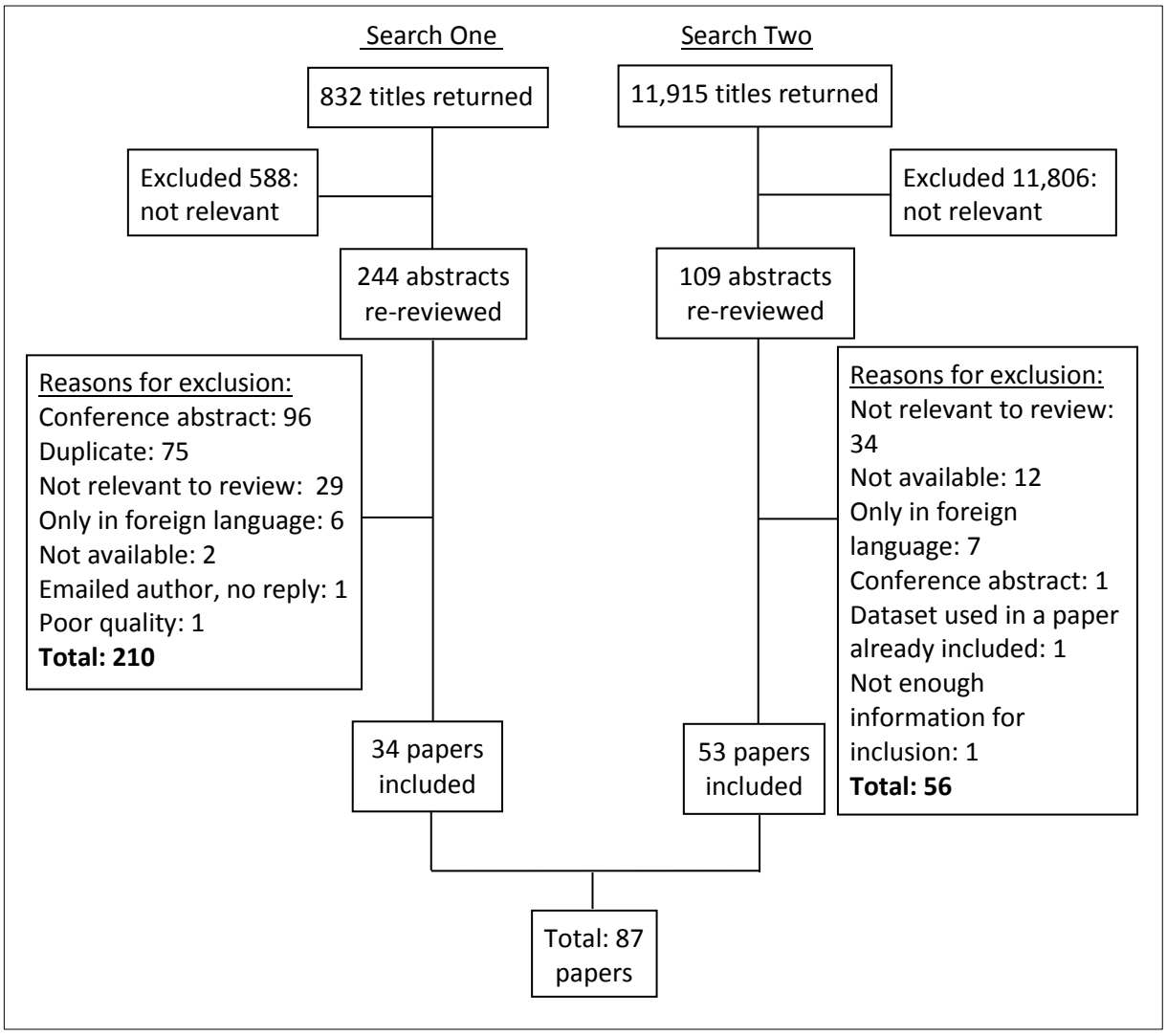

Figure 4 Flowchart displaying the systematic review's search strategy

2.2.3 Inclusion and exclusion criteria

The following inclusion and exclusion criteria were applied at each reviewing stage during the search process:

Studies were included if:

I. They reported the proportion of patients with a final diagnosis of stroke mimics from a sample of suspected or confirmed stroke patients; and
II. They reported on a series of consecutively eligible patients.

Studies were excluded if:

I. They were not available in English;
II. They were 'grey' literature'; or
III. The sample included Transient Ischemic Attack (TIA)-only patients.

2.2.4 Data extracted

Data were extracted on country, study design, data collection, time period, sample size, average age of sample, gender of sample, stroke prevalence, stroke mean age, gender of stroke sample, number of reported stroke mimics, proportion of stroke mimics, mean age of stroke mimics, gender of stroke mimics, proportion of stroke mimics who have a functional disorder, gender of functional disorder patients, mean age of functional patients, the most common stroke mimic diagnosis, site of diagnosis, the method used to diagnose stroke mimics, and whether thrombolysis was administered to stroke mimics.

A quality score was calculated for each study. These were based on a criterion outlined by Kmet et al. (2004) who developed a checklist for judging the quality of quantitative studies. Table 70 ("Appendix 2.1: Checklist for the assessment of quality of quantitative studies") gives this checklist.

There are 14 items scored depending on the degree to which each specific criteria was met ("yes" = 2, "partial" = 1, "no" = 0). Items not applicable to the study design in question were marked "NA" and were not included in the summary score. A summary score was calculated for each paper by summing the total score obtained across all relevant items and dividing by the total possible score.

2.2.5 Statistical analysis

The systematic review data were analysed using Excel Version 14 and SPSS Version 22 (Chicago, IL, USA). Data are expressed as numbers and proportions. Independent sample *t*-tests were used to compare age data between groups and chi-square tests compare gender proportions. *P*-values less than 0.05 were considered statistically significant. Comprehensive Meta-Analysis (CMA) Version 3.3 (Biostat Inc., Englewood, NJ, USA) was used to conduct the meta-analysis. Random-effects models were used to calculate prevalence and summary statistics. This model was used as it assumes variance in effect sizes between studies and makes inferences about the parameters of the population of studies that is likely larger than the set of observed studies (Hedges & Vevea, 1998). The I^2 statistic was used to assess heterogeneity across studies.

2.3 Results

2.3.1 Systematic review

The search returned 87 relevant papers. The average sample size was 808.4 patients. The largest study was a prospective quality improvement initiative at two hospitals in the US with a sample size of 8187 patients (Merino et al., 2013). The smallest study was conducted by Dassan et al. (2012) with 44 patients in total, a prospective study testing the utility of a biomarker in the assessment of stroke.

Articles originated from twenty-two countries, with the US contributing the most studies (*n*=33), followed by the UK (*n*=16) and Germany (*n*=8). Six of the included papers were published in low-income countries. Figure 5 shows the distribution of studies according to their country of origin.

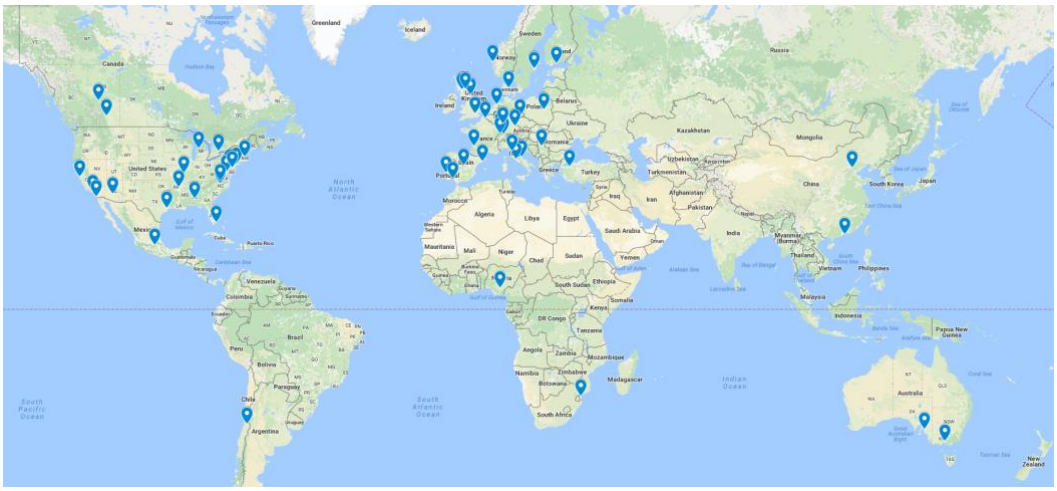

Figure 5 Geographical distribution of regions in which studies were based

75% of studies (*n*=65) were published after 2008, possibly reflecting increasing interest in the topic of stroke mimic patients, government responses' to ageing populations, the increasing economic cost of cardiovascular disease, and the push to improve stroke services. The remaining studies (*n*=22) were published between 1982 and 2007.

Of the medical settings in which studies were based, the most common was the emergency department (*n*=28), followed by stroke units (*n* =15), acute stroke centres (*n*=11), and hospitals (*n*=11). One paper reported stroke mimic rates across three settings (Harbison et al., 2003a) and five papers reported stroke mimic rates across two medical settings (Berglund et al., 2014, El Husseini & Goldstein, 2013, Ferro et al., 1998, Karlinski et al., 2015, & Ramanujam et al., 2008). The rest reported rates from one setting alone.

A prospective study design was employed in 46 (53%) studies and the remainder utilised a retrospective design (*n*=41). The most common type of study was descriptive (*n*=42). Twenty-

four papers were validation studies of screening tools of which five aimed to assess the efficacy of biomarkers in assessing stroke. Twelve studies were audits of services; six investigated the validity of clinicians' diagnostic skills, while the remaining three were descriptive studies.

Data were extracted on whether stroke mimic patients in the study had received thrombolysis treatment. Most commonly, no information was available on whether stroke mimic patients had received thrombolytic treatment (*n* = 54). In 19 studies, all stroke mimic patients received tissue plasminogen activator (rt-PA). In ten studies, stroke mimic patients did not receive any thrombolysis treatment and in four papers, some stroke mimics received treatment while others did not.

The mean quality score was 69.3% (SD: 17.1%, range: 16.6 – 94.4). The paper with the lowest score (16.6%) was Martínez Fernández et al.'s (2012) paper, a prospective paper investigating emergency doctors' diagnostic accuracy. The highest scoring paper (94.4%) was by Foerch et al. (2012), a study investigating the diagnostic accuracy of plasma glial fibrillary acidic protein in distinguishing intracerebral haemorrhage from cerebral ischemia.

2.3.1.1 Exclusion criteria

Exclusion criteria of some kind were applied to study samples in 63 papers, leaving 22 with no recruitment restrictions, and two papers not stating whether they used selection criteria.

The most common exclusion criterion was patients not given thrombolysis treatment (applied in 17 papers), patients with incomplete data (applied in 16 papers), and patients aged under-18 (applied in ten papers). Moeller et al. (2008) excluded patients aged under-16. One paper reported stroke mimic rates in a paediatric sample (Shellhaas et al., 2006) and one study investigated rates in a sample restricted to the over 65's (Kose et al., 2013). Herzberg et al. (2014) excluded patients whose initial clinical exam showed no sign of stroke, potentially leading to a reduced rate of stroke mimic patients.

Table 71-75 (see "Appendix 2.2: Exclusion criteria applied across all studies") outlines all of the exclusion criteria applied in each study.

2.3.1.2 Stroke definitions

Stroke is a heterogeneous disorder and case definitions of stroke and stroke mimics varied across studies. Some studies considered TIA patients in their stroke samples, while others did not.

Twenty papers compared stroke mimic patients to stroke and TIA patients. Fifteen papers classified strokes as 'stroke' with no further detail, twelve examined only ischemic stroke and five examined ischemic stroke, TIA and intracranial haemorrhage patients combined. The rest used a variety of stroke definitions and combinations of stroke types.

In studies where TIA and subarachnoid haemorrhage patients were categorised as stroke mimic patients, these patients were reclassified as stroke for the purposes of this review and meta-analysis (see Table 76, "Appendix 2.3 Definitions of stroke across papers").

2.3.1.3 Stroke mimic diagnoses

Seventy-one papers listed stroke mimic diagnoses.

The stroke mimic diagnosis which was frequently the most common across all studies was seizure (across 22 papers, it was the most frequent diagnosis), followed by functional disorder (the most frequent diagnosis in 14 papers), and migraine (the most frequent diagnosis in eleven papers). See Table 77, "Appendix 2.4: Most common stroke mimic diagnoses across studies" for a breakdown of the most frequently occurring stroke mimic diagnoses.

2.3.1.4 Functional disorder definitions

A range of terms were used to describe patients with functional symptoms. Table 78 ("Appendix 2.5: Functional disorder synonyms across studies") lists the terms used and their frequency of use. The most commonly used term was "conversion disorder" appearing 19 times across studies, followed by the term "functional", occurring ten times, and "psychiatric", which occurred seven times.

One study used the terms "anxiety" and "depression", as well as "conversion disorder" (Ferro et al., 1998). In this study, two patients referred from the emergency department with suspected stroke were later given a diagnosis of anxiety, one was given a diagnosis of depression, and two were given a diagnosis of conversion disorder. While the paper distinguished between these diagnoses in their table, in the text the authors refer to all patients as 'psychiatric'. For the purposes of our review, all three terms were regarded as functional mimic cases.

2.3.1.5 Stroke and stroke mimic demographics

The total number of patients with suspected stroke was 70,333 of whom 55,625 had a stroke diagnosis confirmed and 14,708 were diagnosed with conditions mimicking stroke. Of patients with a stroke mimic diagnosis, 691 had a functional disorder diagnosis.

Fifty papers reported their entire samples' average age, giving a weighted mean of 68.2 years of age (SD: 3.8). Thirty-five papers reported stroke patients' mean age, giving a weighted mean of 69.7 years (SD: 2.2). Thirty-four papers reported stroke mimics' mean age, giving a weighted mean of 63 years (SD: 6). A *t*-test for unequal variances found stroke mimic patients were statistically significantly younger than stroke patients (t = 87.3, df = 6801, two-tailed p = 0.001).

Fifty-one papers gave a gender breakdown of all patients. The total rate of all female patients was 50.2%. Thirty-four papers reported the rate of female stroke patients (46.3%) and 38 papers reported the rate of female stroke mimic patients (56.8%), a significant difference (χ^2 = 227.6, df = 1, p = 0.001).

Table 1 outlines the age and gender of stroke and stroke mimic patients.

Table 1 The age and gender characteristics of stroke and stroke mimic patients

	Total (*n*=70,333)	Stroke patients (*n*=55,625)	Stroke mimic patients (*n*=14,708)	*p* value
Mean age[a] (denominator)	68.2 (40,859)	69.7 (26,017)	63 (6,363)	**0.001**
Female rate (%)[b]	20887/41610 (50.2)	9296/20082 (46.3)	3945/6944 (56.8)	**0.05**

[a] Stroke v. stroke mimic patients: t = 87.3, df = 6801, two-tailed p = 0.001.
[b] Stroke v. stroke mimic patients: χ^2 = 227.6, df = 1, p = 0.001

2.3.1.6 Functional disorder demographics and symptoms

In 16 papers, there was no breakdown of stroke mimic patient diagnoses at all. In five, only a partial account of stroke mimic diagnoses was given. Of the 66 papers giving some form of stroke mimic diagnosis breakdown, in eight, functional disorder was not listed as a diagnosis but the disorder may be masked within the catch-all, miscellaneous categories, termed 'other'. Three papers gave full accounts of stroke mimic patient diagnoses but did not list a functional disorder (signifying a true rate of 'zero' functional disorder events). In total, this left 55 papers reporting positive functional disorder event rates.

One would expect functional disorders to feature as a diagnosis amongst stroke mimic patients. Because of this, the three papers reporting a zero functional disorder rate with no 'other' category were carefully assessed. These are outlined in Table 79 (see "Appendix 2.6: Studies reporting no FND patients in their stroke mimic breakdown"). Two of the three studies (Bray et al., 2005; Kothari et al., 1995) were from ambulatory settings where clinicians may feel less informed or less willing to give a functional diagnosis, particularly given the potential risk in misdiagnosing stroke. Foerch et al.'s (2012) study reported only three stroke mimic patients in total, meaning functional disorders were unlikely to be picked up.

Of the 55 papers reporting a positive functional disorder rate, ten reported the gender profile of functional patients (n=173), eleven reported functional patients' ages (*n* = 177), and nine gave information on presenting symptoms (*n* = 160). From the same pool of participants, data from medical mimics were extracted (i.e. stroke mimic patients with a medical explanation for their symptoms).

Of these patients, the weighted mean age of functional disorder patients was 51.6 (SD: 6.5) while the weighted mean age of medical mimics was significantly higher at 63.8 years (SD: 4.7) (t = 22.8, df = 246, p = 0.001). The pooled proportion of female functional disorder patients 65.9% while the pooled rate of female medical mimic patients was 50.6%, a statistically significant difference (χ^2 =12, df = 1, p = 0.005).

Information on functional patients' presenting symptoms was available from nine papers. The types of symptoms that functional and medical mimics presented with were examined. Patients in both groups could present with more than one symptom. Symptoms were grouped in categories and necessarily, symptom categories became broader so some nuance was lost.

Weakness and numbness were the most common symptom for both functional (63.3%) and medical mimic patients (48.6%), but functional disorder patients were significantly more likely to present with weakness or numbness, and significantly less likely to present with reduced consciousness. From these nine papers, there were no reports of functional mimic patients presenting with seizures or convulsions. Disorders of speech and language comprehension, such as dysarthria, dysphasia and aphasia were the second most common symptom type in both groups.

Table 2 below gives a breakdown of age, gender and symptoms across these studies while Table 80 ("Appendix 2.7: Age and gender of medical mimic and functional mimic patients from studies reporting demographic details") gives a breakdown of rates from each individual study.

Table 2 Age, gender, and symptom differences between medical and functional mimic patients

	Medical mimics n (%)	Functional mimics n (%)	*p* value
Total *n*	482	177	
Mean age (SD)[a]	63.8 (4.7)	51.6 (6.5)	**0.05**
Females[b]	243 (50.6)	114 (65.9)	**0.05**
Symptoms[b]			
Weakness or numbness	287 (48.6)	167 (63.3)	**0.05**
Reduced consciousness	46 (7.8)	7 (2.7)	**0.001**
Posterior circulation	35 (5.9)	16 (6.1)	> 0.05
Visual symptoms	35 (5.9)	11 (4.2)	> 0.05
Dysarthria, dysphasia, aphasia or anomia	101 (17.1)	41 (15.5)	> 0.05
Seizures or convulsions	2 (0.3)	0 (0)	> 0.05
Cognitive impairment, confusion, or memory loss	40 (6.8)	14 (5.3)	> 0.05
Vertigo	44 (7.5)	8 (3)	**0.01**

[a] *t*-test
[b] Chi-square test
[c] Age data available in 11 papers, symptom data available from 9 papers

2.3.1.7 Accounting for 'other' categories

In 33 papers, a full breakdown of stroke mimic diagnoses was not given and the miscellaneous category 'other' was used. It was hypothesized that papers which did not list functional disorder at all might have counted the disorder within the diagnostic category, 'other'. In order to examine this, the 'other' rate was compared in papers listing both a functional disorder rate and an 'other' rate to papers listing an 'other' rate but no functional disorder rate.

Twenty-one papers listed both categories. In these papers, the average functional disorder rate was 12.5% and the average 'other' rate was 17.05%. Twelve papers listed an 'other' rate but no functional disorder rate. The mean 'other' rate in these papers was significantly higher, nearly twice as high at 31.6% compared to the 17.05% in papers listing both 'other' and functional disorder rates, representing a significant difference ($\chi^2 = 116.4$, $df = 1$, $p < 0.001$) (see Table 3).

Table 3 Difference in average rates of 'other' categories between papers listing an 'other' category but no 'functional disorder' rate with papers listing both categories

	Studies *n*	Functional disorder %	'Other' rate %
Papers with a 'functional disorder' category & an 'other' category listed	21	12.5	17.05*
Papers with no 'functional disorder' category listed, but 'other' category listed	12	-	31.6*

*Significant difference between 'other' rates ($\chi^2 = 116.4$, $df = 1$, $p < 0.001$)

This supports the hypothesis that functional disorder patients may be hidden within the category 'other' when no functional disorder category is listed.

2.3.2 Meta-analysis

Three meta-analysis calculations were conducted:

I. Analysis one assessed the proportion of suspected stroke patients who were later confirmed as stroke mimic patients (*n* included studies = 87);

In the calculation of the functional disorder rate, papers with no stroke mimic breakdown at all (*n* = 16) and papers with only partial accounts of stroke mimics (*n* = 5) were excluded. Further calculations were as follows:

II. Analysis two included all studies, including the eight papers which listed no functional disorder rate but where it is possible functional disorders were hidden within papers' self-described 'other' category (*n* studies = 66);
III. Analysis three excluded the eight papers where functional disorders are not listed but which have an 'other' category (*n* studies = 58).

Random effects models were used and included the three papers which gave full accounts of stroke mimics, did not include an 'other' category but where functional disorder was not listed. The findings were as follows:

I. Analysis one: There were 70,333 suspected stroke patients and 14,708 of these were stroke mimic patients. Using a random effects model from all 87 papers, the pooled proportion of stroke mimic patients was 17.9% (95% CI: 15.5% to 20.6%), with high between study heterogeneity (I^2: 98.6%).
II. Analysis two: The total number of suspected stroke patients eventually diagnosed with a functional disorder was 691. The pooled prevalence of functional disorder as a proportion of all suspected stroke patients was 1.7% (95% CIs: 1.3% - 2.2%, I^2: 89.7%). The pooled proportion of functional disorders as a proportion of stroke mimic patients was 11.8% (95% CIs: 9.3% - 14.9%, I^2: 86.9%).
III. Analysis three: With the removal of the eight studies with an 'other' category, the pooled prevalence of functional disorders as a proportion of stroke mimic patients increased to 13.9% (95% CIs: 11% - 17.4%, I^2: 87%).

Potential sources of heterogeneity were explored using stratified analyses. These are outlined below.

2.3.2.1 Diagnosis site

I. Analysis one

When taking the diagnostic setting into account the pooled proportion varied. The overall heterogeneity remained high. The highest proportion of stroke mimic patients were diagnosed in primary care or outpatients setting (36.4% of suspected stroke patients, 95% CI: 21% - 55.3%), followed by the 'EMS' setting (emergency medical services) (35.1%, 95% CI: 21.5% - 51.7%), ambulances (28.8%, 95% CI: 19.2% – 40.7%), and the lowest rate of stroke mimic patients were diagnosed at stroke units (6.5%, 95% CI: 4.3%- 9.9%). Figure 6 displays the stroke mimic rates across settings.

Figure 41 (See "Appendix 2.8: Stroke mimic forest plot") displays a forest plot showing the full breakdown of rates from individual studies according to the study setting.

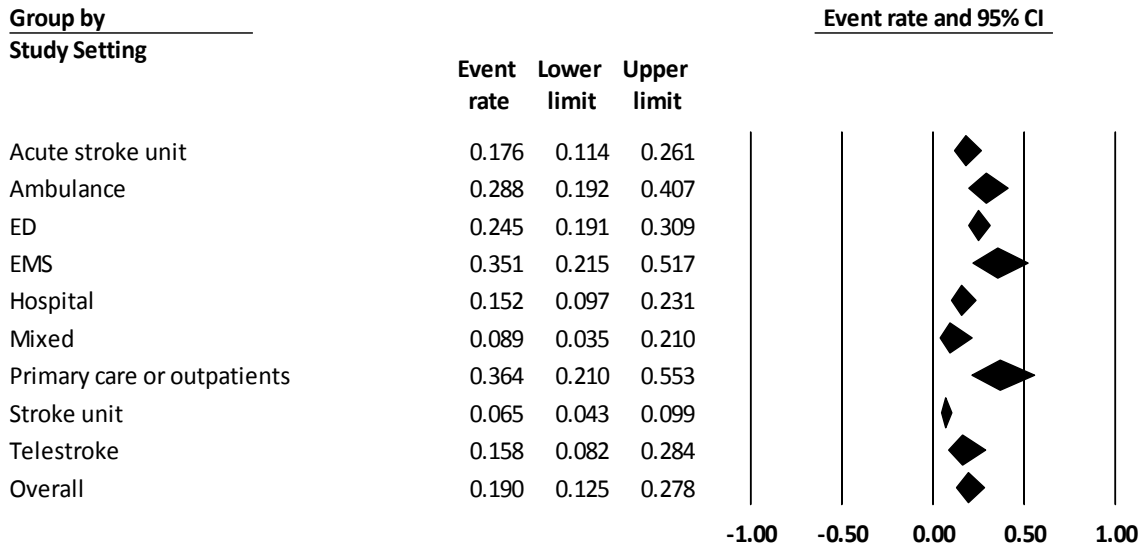

Figure 6 Forest plot displaying the proportion of stroke mimic patients diagnosed at acute stroke unit, ambulance, emergency department (ED), emergency medical services (EMS), hospitals, mixed settings, primary care or outpatient settings, stroke unit, and telestroke settings

II. Analysis two

Analysis two included papers which reported no functional disorder but which reported an 'other' category. The setting from which functional disorder patients were most frequently diagnosed was the stroke unit (25.3% of stroke mimics, 95% CIs: 15.6% - 38.3%, I^2: 77.7%). The setting with the least frequently diagnosed functional disorder patients was the 'EMS' setting (2.4%, 95% CIs: 0.3% - 16.4%, I^2: 77.1%).

Figure 7 outlines the proportion of functional disorder patients diagnosed from stroke mimic patients according to the medical setting in which they were diagnosed.

Figure 42 (Appendix 2.9: Functional stroke mimic forest plot) displays the proportion of functional stroke mimic patients and the individual studies from which rates were taken.

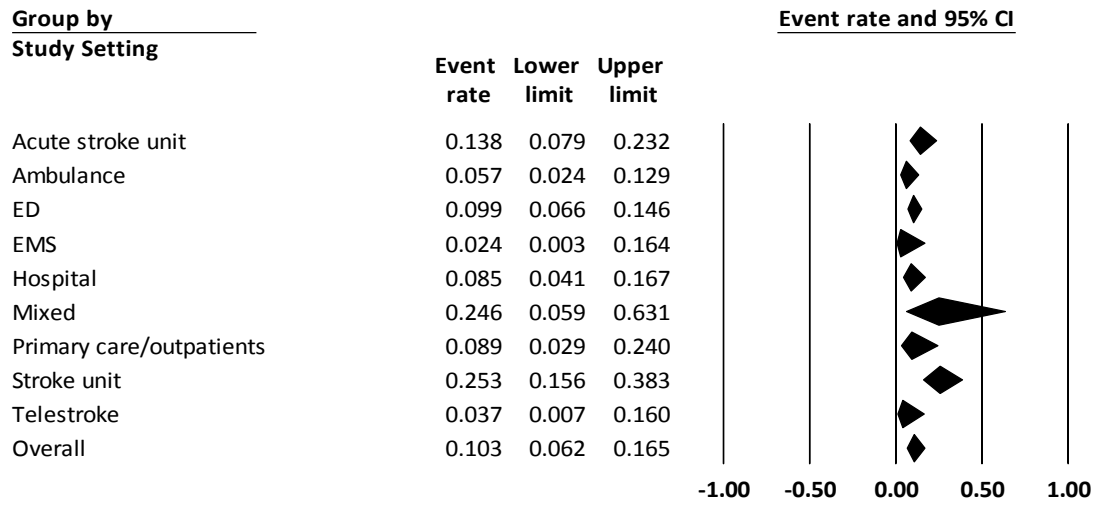

Figure 7 Forest plot displaying the proportion of functional disorder patients diagnosed from stroke mimic patients according to medical setting

III. Analysis three

With the removal of the eight papers reporting no functional disorder cases but which included an 'other' category, functional disorder rates increased slightly (with the exception of the 'EMS' setting). See Figure 8 for a breakdown of each functional disorder rate according to the setting in which the study took place.

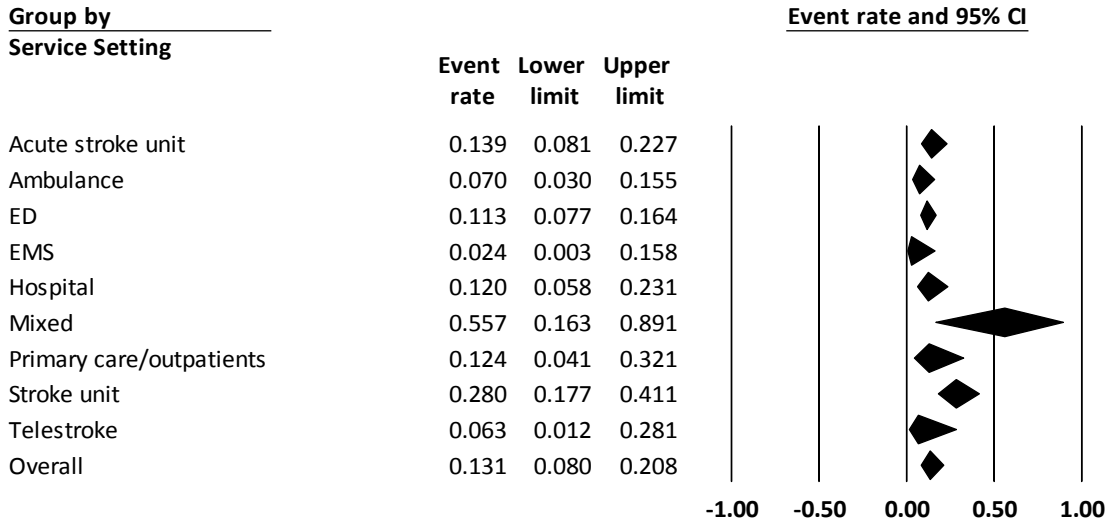

Figure 8 Forest plot displaying the proportion of functional disorder patients diagnosed from stroke mimic patients according to medical setting with papers removed which report no functional disorder cases, but do give an 'other' category

2.3.2.2 Study design

I. Analysis one

The effect of study design on the rate of stroke mimic patients was investigated. Studies were categorised as utilising either prospective or retrospective designs; 46 (52.9%) papers were prospective and 41 (47.1%) were retrospective.

The pooled proportion of stroke mimic patients from studies using a retrospective design was lower (12.6%, 95% CIs: 10.1% – 15.6%, I^2: 98.8%) than studies using prospective methods (23.9%, 95% CIs: 19.9% - 28.4%, I^2: 98.2%). Figure 9 shows the rate of stroke mimic patients according to the study design used.

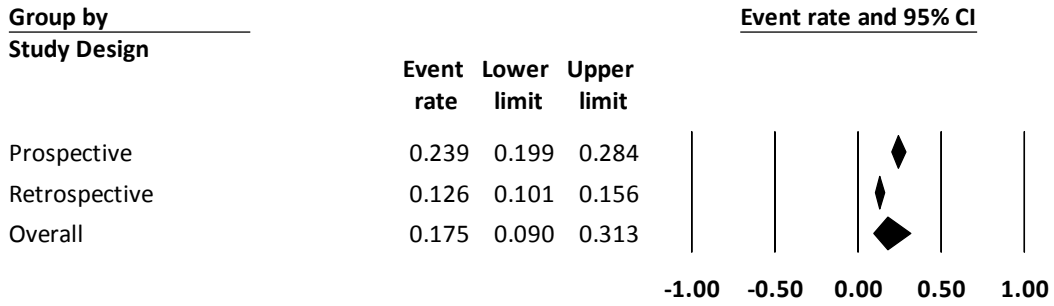

Figure 9 Forest plot displaying the proportion of stroke mimic patients according to studies' study design

II. Analysis two

Taking the 66 papers reporting a functional disorder rate, there were similar proportions of prospective (48.5%) and retrospective studies (51.5%).

The pattern was reversed as papers employing retrospective study designs had a higher rate of functional disorder (15.7%, 95% CIs: 11.3% - 21.3%, I^2: 89%) than prospective studies (8.9%, 95% CIs: 6.3% - 12.5%, I^2: 81%). Figure 10 displays the forest plot of functional disorder rates, as a proportion of stroke mimics, according to study design.

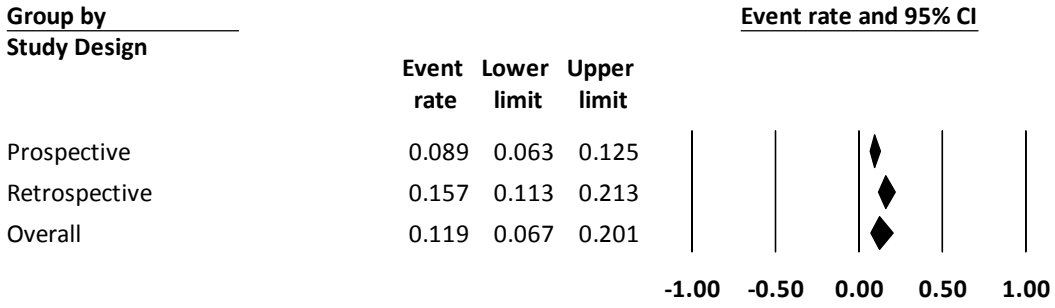

Figure 10 Forest plot displaying the proportion of functional disorder patients diagnosed from stroke mimic patients according to study design

III. Analysis three

When the eight studies reporting no functional disorder rates but 'other' categories were removed, again rates in both groups increased, with the retrospective studies reporting a functional disorder rate of 18.5% (95% CIs: 13.5% - 24.8%, I^2: 89%). The prospective studies reported a rate of 10.3% (95% CIs: 7.4% - 14.3%, I^2: 80.8%). Figure 11 displays the overall forest plot for studies.

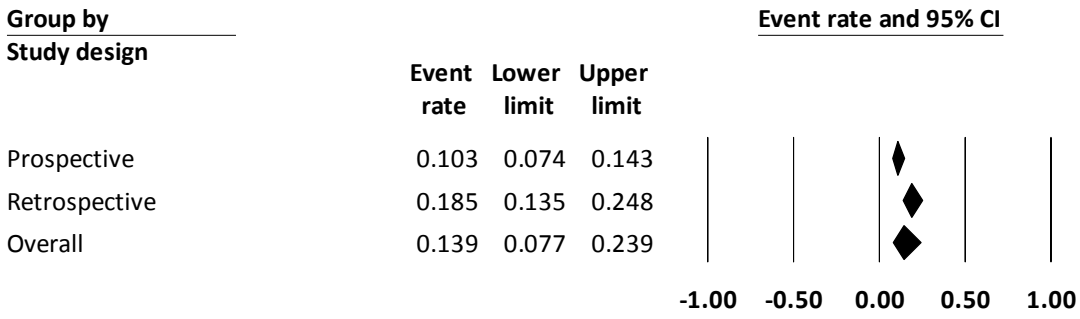

Figure 11 Forest plot displaying the proportion of functional disorder patients according to study design with papers removed which report no functional disorder patients but which list an 'other' category

2.3.2.3 Exclusion criterion

Some studies applied exclusion criteria to the sample under investigation (see "Appendix 2.2: Exclusion criteria applied across all studies"). Sixty-three papers (72.4%) applied some form of exclusion criterion to their overall sample, 22 applied no exclusion criteria (25.3%) and two papers (2.3%) gave no information on exclusion criteria.

I. Analysis one

Studies applying exclusion criteria to their sample had a lower pooled stroke mimic prevalence at 16.4% (95% CIs: 13.7% - 19.4%, I^2: 98.7%) than the 22 papers with no exclusion criteria at 21.1% (95% CIs: 15.9% - 27.4%, I^2: 98.2%), see Figure 12.

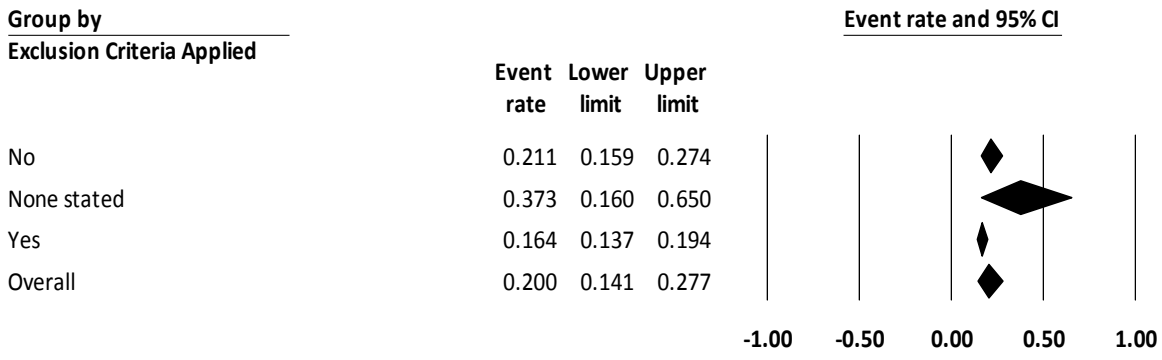

Figure 12 Forest plot displaying the proportion of stroke mimic patients according to whether a sample exclusion criterion was applied

II. Analysis two

The trend was reversed when the rate of functional disorder patients amongst stroke mimic patients was investigated. Forty-eight studies (72.7%) applied exclusion criteria while 16 (24.2%) did not. Studies applying no exclusion criteria had an overall functional disorder prevalence of 9.2% (95% CIs: 5.5% - 14.7%, I^2: 89.5%). The studies applying one or more exclusion criterion to the study sample reported a functional disorder rate of 13.2% (95% CIs: 9.9% - 17.4%, I^2: 85.4%). This is outlined in Figure 13.

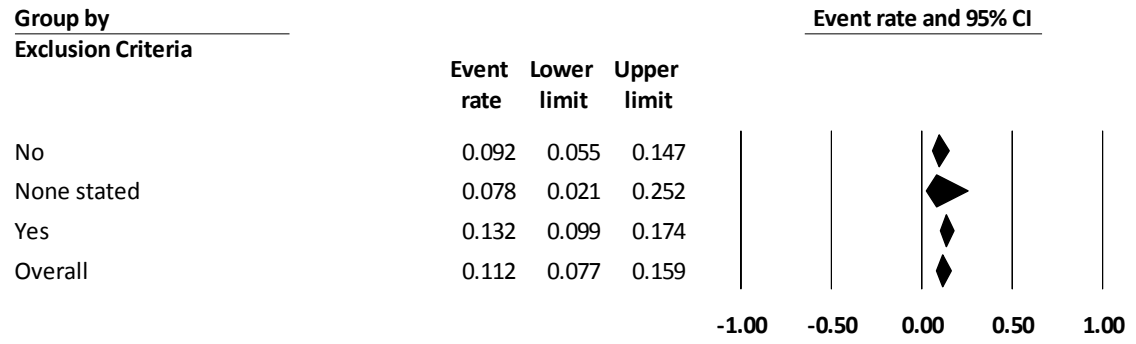

Figure 13 Forest plot displaying the proportion of functional disorder patients diagnosed from stroke mimic patients according to study design

III. Analysis three

When the eight studies were removed, again, functional disorder rates increased slightly with studies applying no exclusion criteria reporting a prevalence rate of 10.8% (95% CIs: 6.6% - 17.1%, I^2: 89.7%). Papers in which one or more exclusion criterion was applied had a functional disorder rate of 15.6% (95% CIs: 11.8% - 20.4%, I^2: 85.8%), see Figure 14.

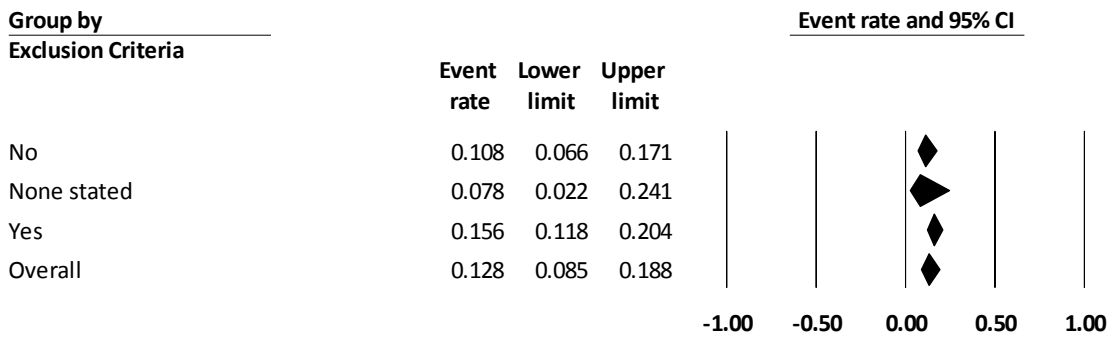

Figure 14 Forest plot displaying the proportion of functional disorder patients diagnosed from stroke mimic patients according to exclusion criteria with papers removed which report a zero functional disorder rate but an 'Other' category

2.3.2.4 Countries' economic status

I. Analysis one

Stroke mimic prevalence rates were compared based on whether they were conducted in high or low income countries. Seventy-seven papers (88.5%) were published in countries with high income economies. Six originated in low income economies (6.9%). Three (3.4%) were categorised as 'mixed' meaning their rates came from more than one country which included both high and low income states and one was not known (1.1%).

Rates in both high and low income groups were very similar with a slightly higher pooled proportion of 19.4% for stroke mimic patients (95% CIs: 16.9% - 22.1%, I^2: 98.3%) from higher income countries compared to lower income countries at 18.9% (95% CIs: 11.5% - 29.5%, I^2: 98.9%), see Figure 15.

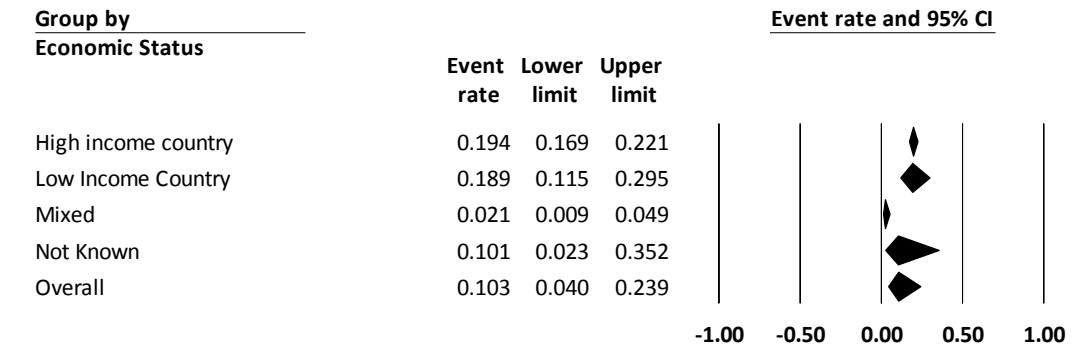

Figure 15 Forest plot displaying the proportion of stroke mimic patients according to the economic status of the country in which the study was based

II. Analysis two

In high income countries the pooled rate of functional disorder amongst stroke mimics was 12.4% (95% CIs: 9.7% - 15.7%, I^2: 86.7%), almost four times higher than the rate in studies from low income countries at 3% (95% CIs: 1.1% - 8%, I^2: 25.3%). In two papers, studies were from

mixed settings and these reported the highest pooled prevalence rate at 43.2% (95% CIs: 15.3% - 76.1%, I^2: 78.4%), see Figure 16.

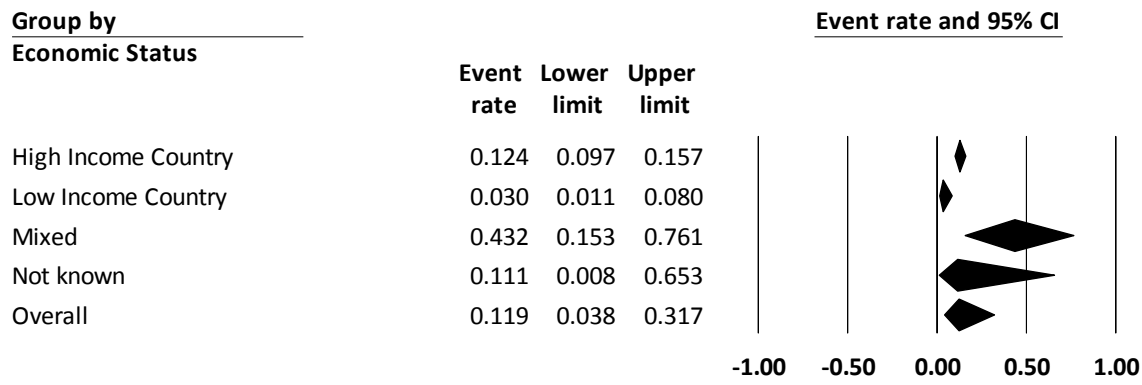

Figure 16 Forest plot displaying the proportion of functional disorder patients diagnosed from stroke mimic patients according to economic status of the country in which the study was conducted

III. Analysis three

When the eight studies were removed from the analysis, all functional disorder rates increased, with high income countries with a functional disorder rate of 14.1% (95% CIs: 11.1% - 17.8%, I^2: 86.8%) and low income countries with a functional rate of 4.2% (95% CIs: 1.5% - 11.7%, I^2: 0%), see Figure 17.

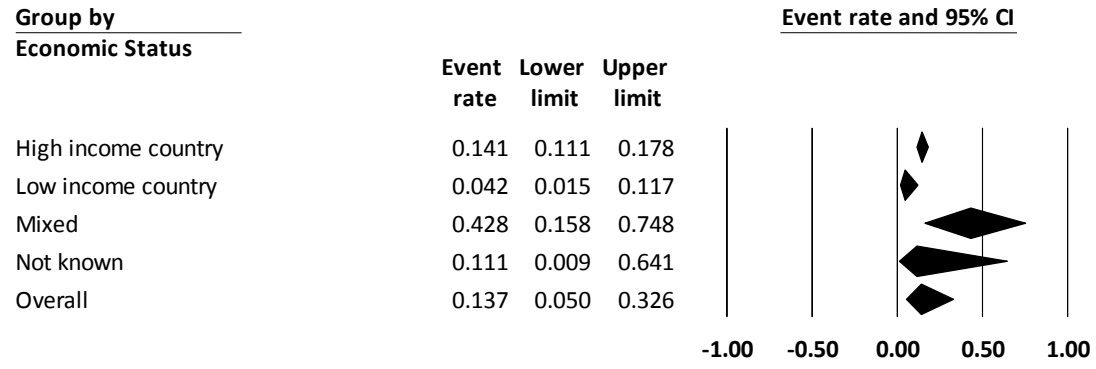

Figure 17 Forest plot displaying the proportion of functional disorder patients diagnosed from stroke mimic patients according to economic status of the country in which the study took place with papers removed which report a zero functional disorder rate but also an 'other' category

2.3.2.5 Thrombolysis treatment

Studies were categorised based on whether stroke mimic patients had received thrombolysis or not. Fifty-four studies did not state whether this treatment had been given. In four studies, some stroke mimic patients received the treatment while others did not. In 19 papers, all stroke mimic patients received thrombolysis.

I. Analysis one

In studies where stroke mimic patients received thrombolysis, the pooled prevalence of stroke mimic patients was 5.9% (95% CIs: 4.2% - 8.1%, I^2: 95.5%) but higher in studies where stroke mimic patients did not receive thrombolysis (22.6%, 95% CIs: 15.6% - 31.5%, I^2: 96.7%), see Figure 18.

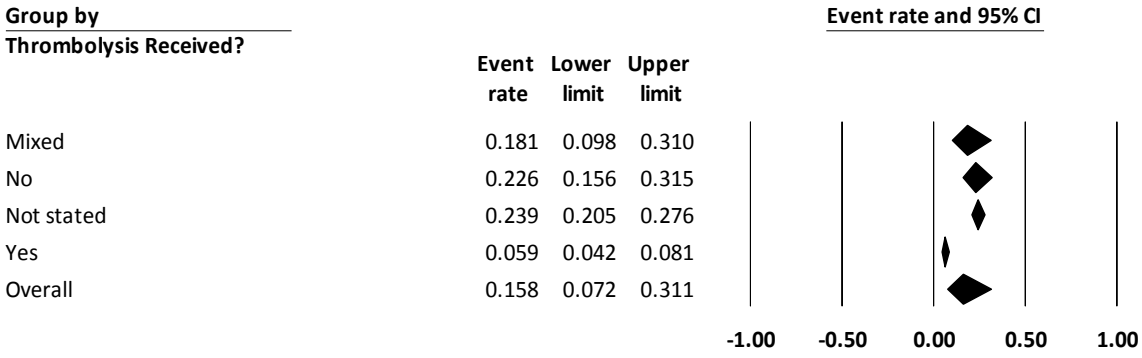

Figure 18 Forest plot displaying the proportion of stroke mimic patients according to whether they received thrombolysis treatment

II. Analysis two

There was a considerable difference in rates of functional disorder based on whether thrombolysis had been given. In studies where stroke mimic patients had received thrombolysis, 33.3% (95% CIs: 24.2% - 43.7%, I^2: 71.1%) of patients had a functional disorder diagnosis. In studies where patients had not received thrombolysis the functional disorder rate was 5.5% (95% CIs: 3% - 9.8%, I^2: 9.4%), see Figure 19.

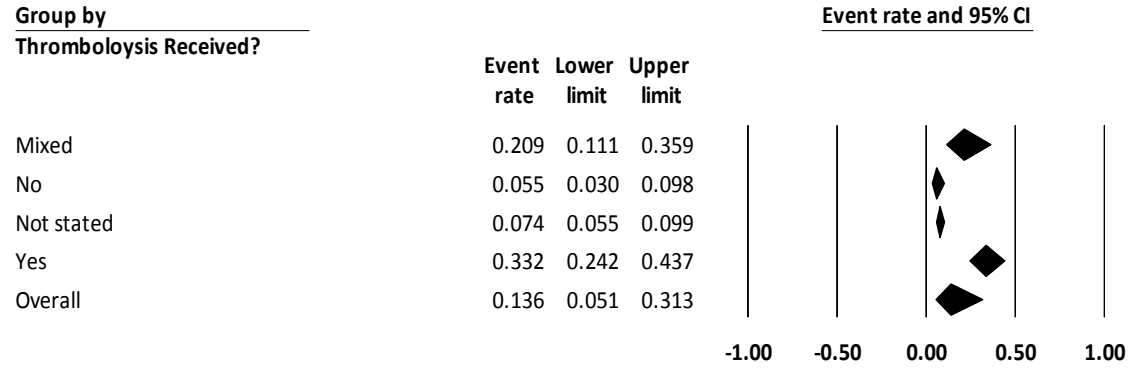

Figure 19 Forest plot displaying the proportion of functional disorder patients diagnosed from stroke mimic patients according to whether the patients received thrombolysis treatment or not

III. Analysis three

With the removal of the eight papers reporting no functional disorder but which included an 'other' category, the functional disorder rate for patients who received no thrombolysis

treatment increased to 6% (95% CIs: 3.3% - 10.6%, I^2: 0%), but remained the same for those who did receive thrombolysis at 33.1% (95% CIs: 24.4% - 43.2%, I^2: 71.1%), see Figure 20.

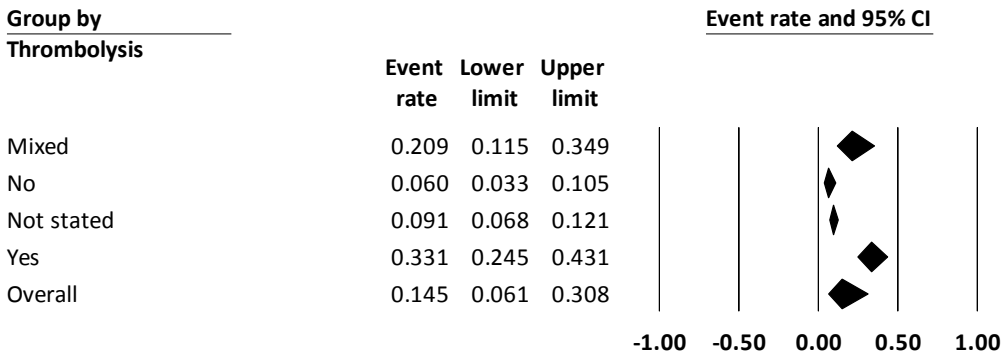

Figure 20 Forest plot displaying the proportion of functional disorder patients diagnosed from stroke mimic patients according to whether patients were given thrombolysis with papers removed which report no functional disorders but list an 'other' category

2.3.2.6 Year of publication

The year of studies' publication was categorised by decade: '1980 to 1989', '1990 to 1999', '2000 to 2009' and '2010 to 2016'.

I. Analysis one

The pooled prevalence of stroke mimic patients was highest in the years between 2000 and 2009 (23.2%, 95% CIs: 18% - 39.4%, I^2: 98.5%). The lowest rate was reported from papers published between 1990 and 1999 (9.3%, 95% CIs: 5.2% - 16.1%, I^2: 96.3%). See Figure 21 for more details.

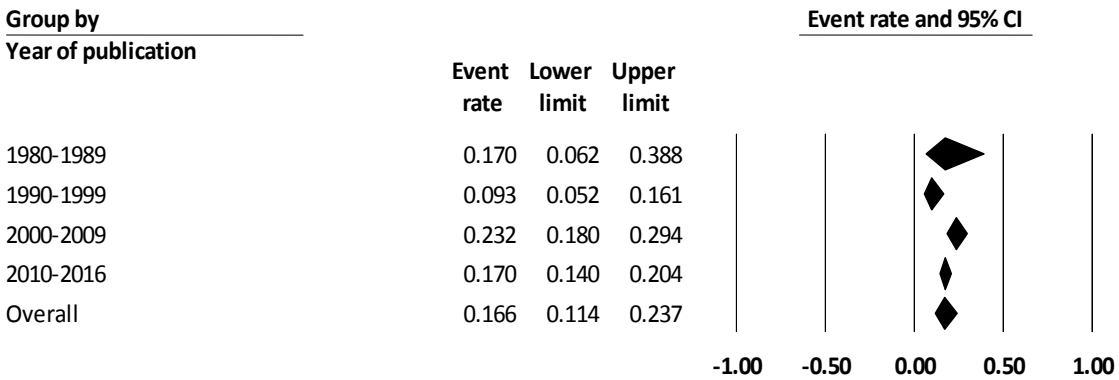

Figure 21 Forest plot displaying the pooled proportion of stroke mimic patients by publication year

II. Analysis two

The rate of functional disorder as a proportion of stroke mimic patients increased over time (Figure 21). Between 1980 and 1989, two papers reported functional disorder rates at 2.8% (95% CIs: 0.6% - 13.3%, I^2: 86.5%), between 1990-1999 the rate increased to 8.2% (95% CIs: 3.3% - 19.1%, I^2: 70.2%), between 2000-2009 it was at 10.1% (95% CIs: 6.5% - 15.5%, I^2: 80%) and between 2010 and 2016 it was 14.2% (95% CIs: 10.5% - 19%, I^2: 89%), see Figure 22.

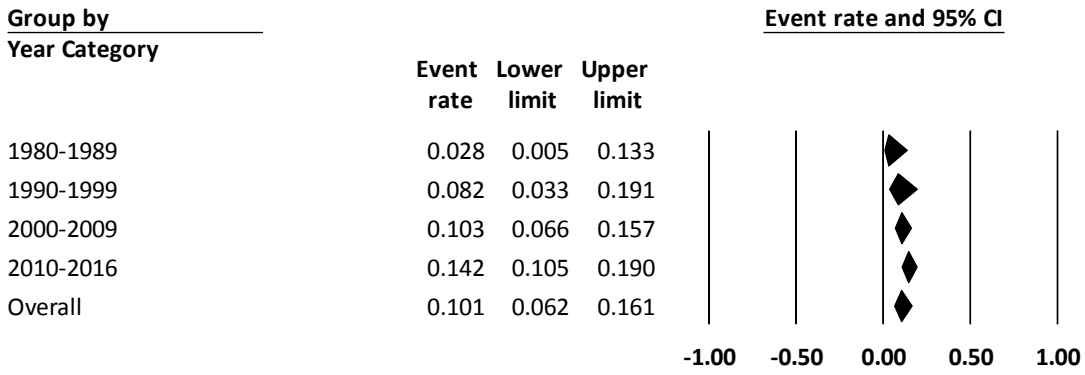

Figure 22 Forest plot displaying the pooled proportion of functional disorder patients from stroke mimic patients by publication year

III. Analysis three

With the removal of the eight studies with no functional disorder rates but 'other' categories, all functional disorder rates increased and there was an increasing trend over time with the rate of functional disorders at 7.4% (95% CIs: 1.3% - 33.5%, I^2: 0%) in studies published between 1980 and 1989 and at 17.3% (95% CIs: 12.9% - 22.8%, I^2: 89.7%) in published papers between 2010 and 2016. The overall functional disorder rate was 12.1% (95% CIs: 7.4% - 18.9%, I^2: 87.2%), see Figure 23.

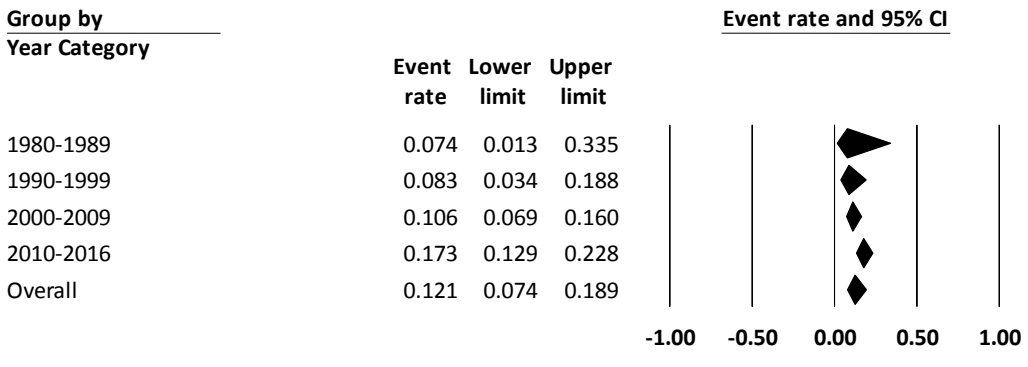

Figure 23 Forest plot displaying the proportion of functional disorder patients diagnosed from stroke mimic patients according to the year category in which the paper was published with papers removed which report no functional disorder rate but include an 'other' category

2.3.2.7 Study aim

The overall aim of each study was categorised into six categories to assess the effect of studies' aims on the variability of prevalence rates.

I. Analysis one

The highest proportion of stroke mimics was reported from studies which had more than one aim, categorised as 'mixed' (*n* studies = 3) at 38.8% (95% CIs: 20.8% - 60.4%, I^2: 96.5%). The lowest rate was reported from descriptive studies at 13.9% (95% CIs: 11.2% - 17%, I^2: 98.7%), see Figure 24.

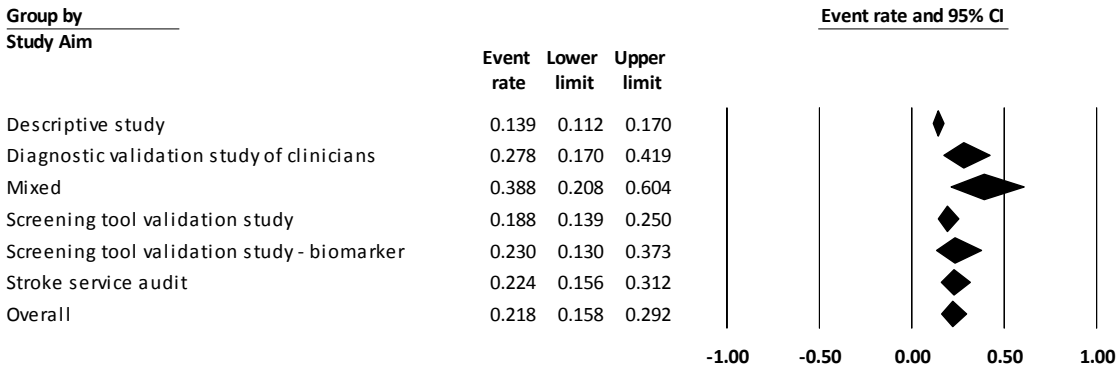

Figure 24 Forest plot displaying the pooled prevalence of stroke mimic patients according to the intended aim of study papers

II. Analysis two

The highest functional disorder rate, as a proportion of stroke mimic patients, was reported in descriptive studies at 15.1% (95% CIs: 11.1% - 20.2%, I^2: 89.5%) and the lowest in clinician diagnostic validation studies 6.1% (95% CIs: 1.9% - 18.2%, I^2: 82.5%), see Figure 25.

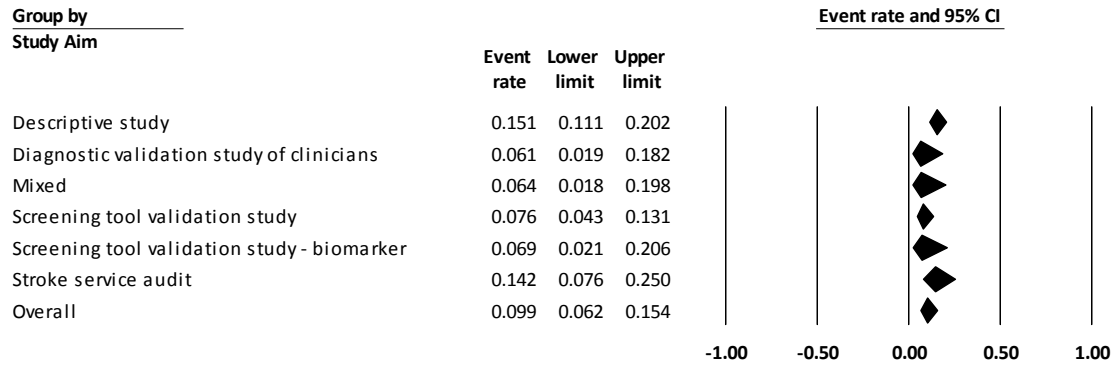

Figure 25 Forest plot displaying the pooled prevalence of functional disorder patients according to the intended aim of studies

III. Analysis three

Removing the eight studies with an 'other' category saw a slight increase in all rates with descriptive studies reporting the highest functional disorder rate at 17.6% (95% CIs: 13.1% - 23.2%, I^2: 89.8%) and clinician diagnostic validation studies also showing a slight increase in proportion at 10.1% (95% CIs: 3% - 28.6%, I^2: 78.5%) (see Figure 26).

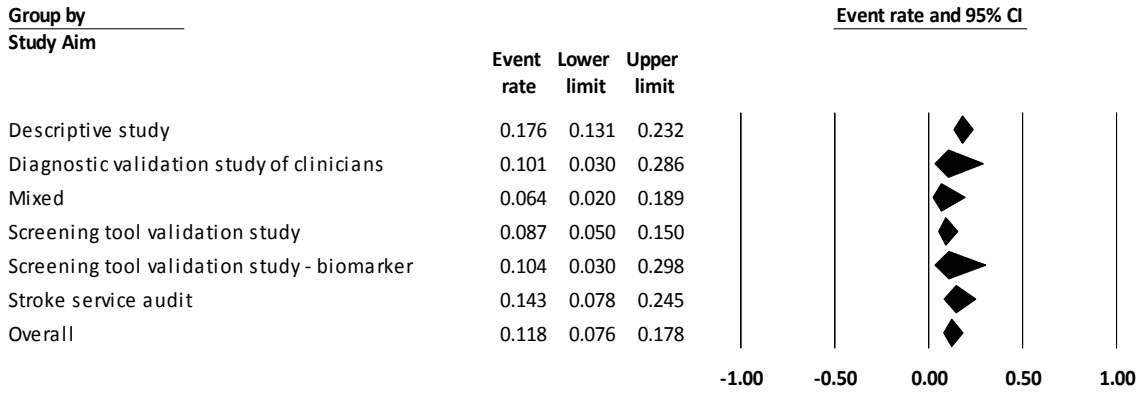

Figure 26 Forest plot displaying the proportion of functional disorder patients according to the papers' reported aim with papers removed which report no functional disorder rate but include an 'other' category

2.3.2.8 Quality score

Quality scores were categorised into nine groups (11-20%, 21-30% etc.). The mean quality score was 69.3% (SD: 17.1%, range: 16.6 – 94.4).

There was no correlation between studies' sample size and their quality score.

I. Analysis one

There was no clear trend in prevalence rates according to quality score. Only one study was given a rating between 11-20% and one study was rated between 21-30%. The highest reported stroke mimic rate came from studies rated between 21-30%. The lowest stroke mimic rate came from papers scored between 51-60% (8.3%, 95% CIs: 4.4% - 15%, I^2: 97.2%), see Figure 27.

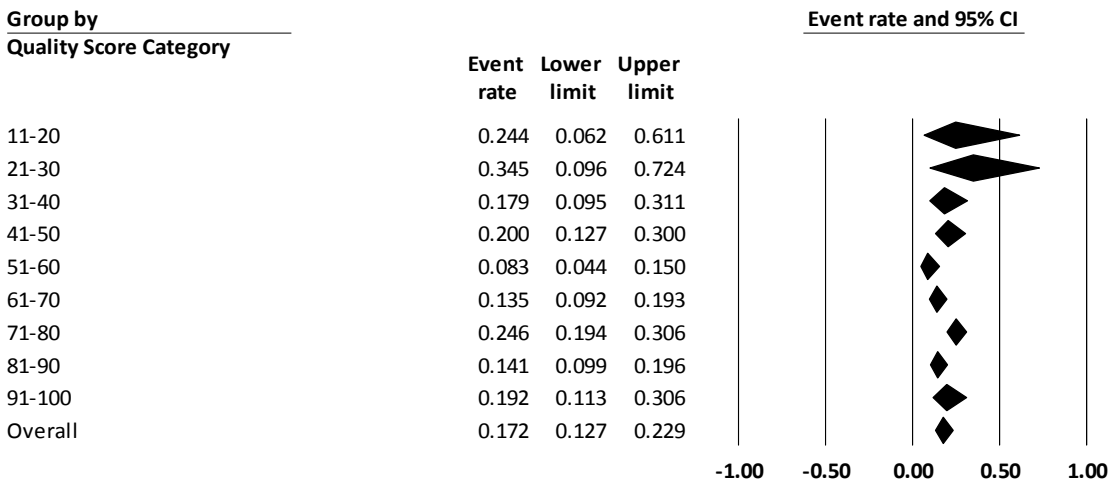

Figure 27 Forest plot displaying the pooled prevalence of stroke mimic patients according to the quality category into which they fell

II. Analysis two

The same calculations were conducted for rates of functional disorder patients amongst stroke mimic patients. The highest rate of functional disorder were in papers rated between 51-60% (95% CIs: 5.9% - 34.8%, I^2: 85.8%). The lowest rate was in studies rated 21-30% at 9.9% (95% CIs: 4.5% - 20.4%, I^2: 0%) (although only one study scored within this quality category). See Figure 28 for a full breakdown of prevalence rates according to quality score categories.

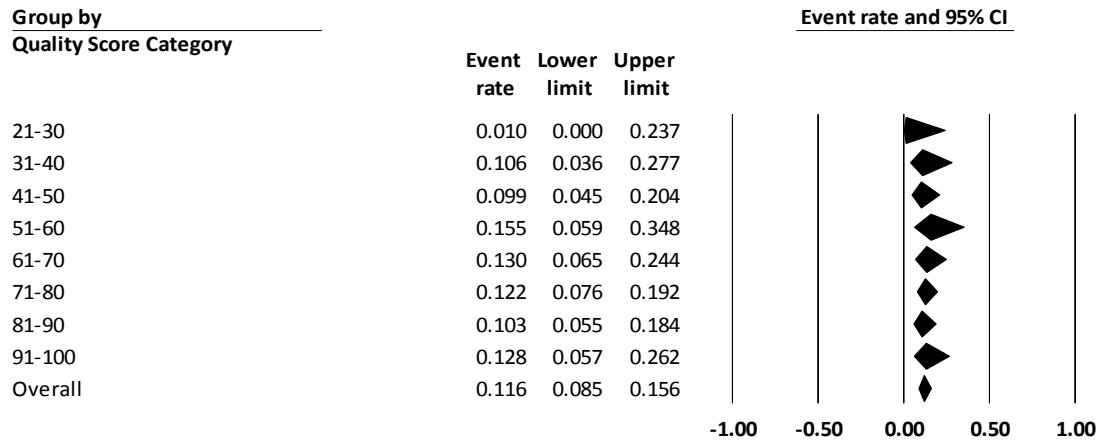

Figure 28 Forest plot displaying the pooled prevalence of functional disorder patients according to their quality category

III. Analysis three

With the removal of the eight studies reporting no functional disorders but listing an 'other' category, the lowest rate of functional disorder were those given quality scores between 41-50% group with a prevalence rate of 9.9% (95% CIs: 4.6% - 19.9%, I^2: 84%). The highest rate of functional disorder patients were from those studies rated between 51-60% group at 19.1% (95% CIs: 7.3% - 41.2%, I^2: 83.3%). See Figure 29.

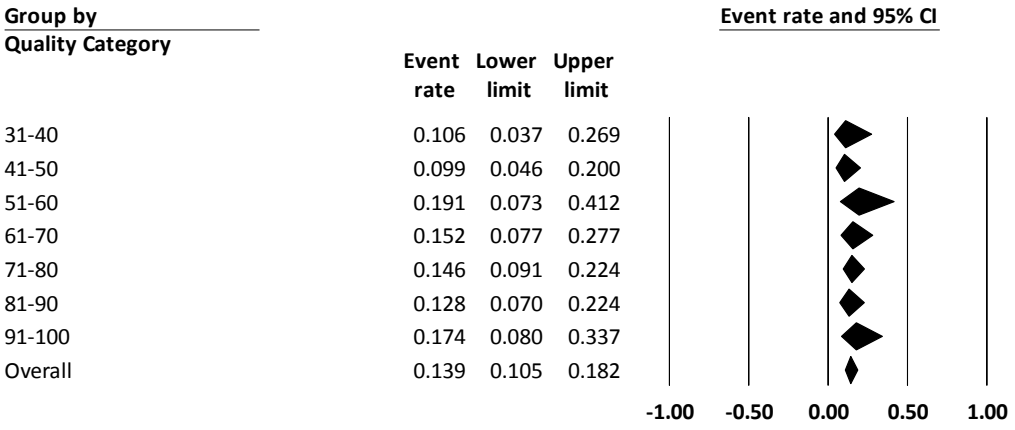

Figure 29 Forest plot displaying the proportion of functional disorder patients according to papers' assigned quality score with papers removed which report no functional disorder patient rate but an 'other' category

2.4 Discussion

2.4.1 Main findings

This chapter aimed to estimate the prevalence of stroke mimic patients who present to stroke services and the proportion of these patients who have a functional explanation for their symptoms.

Stroke mimic patients make up a significant proportion of patients with suspected stroke at 17.9% (95% CI: 15.5 to 20.6%). Of stroke mimic patients, 11.8% (95% CIs: 9.3 - 14.9%) are functional disorder patients. When studies with an 'other' category and no functional diagnosis are removed from the analysis, the rate of functional disorders increases to 13.9% (95% CIs: 11 - 17.4%). Functional patients represent 1.7% of all suspected stroke patients. Our functional disorder rates are likely an underestimate as many studies do not report functional cases but provide 'other' or 'unknown' categories, among whom a proportion are likely to be functional.

Our stroke mimic rate is lower than the 26% reported in Gibson and Whiteley's (2013) paper while our functional rate is higher. Gibson and Whiteley (2013) restricted their analysis to prospective research and included only 29 studies. Our stroke mimic rate from prospective studies alone was 23.9%. Our review also extends the definition of functional disorders, including patients with depression and anxiety diagnoses.

Stroke patients were less likely to be female than stroke mimic patients (46.3% versus 56.8%) and medical mimics were less likely to be female than functional mimic patients (50.6% versus 65.9%) both representing significant differences in proportions.

This finding is not unexpected. It is well established that stroke more commonly affects males than females. The global male stroke prevalence is 41% higher than female stroke prevalence (Appelros et al., 2009). In addition, there is consistent evidence that functional symptoms more commonly affect women, a finding replicated in most epidemiological studies and across multiple settings such as neurology (Stone et al., 2010a), general practice (De Waal et al., 2004; El Husseini & Goldstein, 2013; Faravelli et al., 1997), and general hospitals (Deka et al., 2007). Nimnuan et al.'s (2001) study found females were twice as likely as men to have medically unexplained symptoms across seven medical specialities.

Stroke patients had an average age of 69.7 years while stroke mimic patients were on average seven years younger. Medical mimics' mean age was 63.8 years while functional mimics were significantly younger with a mean age of 51.6 years. These findings correspond with previous findings. Appelros et al.'s (2009) study report a mean age of stroke onset of 68.6 years for men and 72.9 years for women, and functional disorder patients in neurology settings have a mean age of 43 years (Stone et al., 2010), although it is likely these symptoms begin earlier.

Functional patients are more likely to present with weakness and numbness and less likely to have reduced consciousness or vertigo. Weakness and numbness are defined by absence of a function. It is plausible that a clinician, faced with an absence of physical function and no clear imaging evidence, might be more likely to classify these symptoms as functional despite more recent calls for positive signs to be employed when making a functional diagnosis (Stone, Carson, & Sharpe, 2005).

The diagnosis of functional disorder, until recently, required clinicians to identify a potential psychological reason for symptoms and the disorder necessitates some kind of patient/clinician interaction. This may influence the kind of symptoms described as functional. A clinician assessing a potential functional patient with reduced consciousness won't be able to gain a psychological history and such a patient may be less likely to receive the functional diagnosis.

Vertigo, which can occur as part of a functional presentation, may be regarded by stroke clinicians as a stand-alone diagnosis and clinicians may feel making further investigations or exploring the possibility of a functional diagnosis may be unwarranted or unnecessary.

A high proportion of studies included in this review list stroke mimic diagnoses but the primary purpose of these studies was to improve the accuracy and speed of the diagnosis and treatment of stroke. Of the 87 papers reporting stroke mimic rates, 24% gave no or only partial outlines of stroke mimic diagnoses. Even less information is available on functional disorders. Only eleven studies gave information on the gender and age of functional patients and there

was no consistent evidence on the type of symptoms functional patients presented with or their clinical outcomes. As a result, this study will be necessarily limited in its scope.

Rates vary depending on the kind of setting in which you look, the kind of study used and the year in which the study took place. The following section discusses the results from the stratified analyses.

2.4.2 Stratified analysis

2.4.2.1 Diagnosis site

There was considerable variability in the rate of stroke mimic patients depending on the kind of service making the diagnosis. As might be expected, stroke mimic patients are most commonly identified by clinicians at the early stages of the stroke care pathway, in the ambulatory, emergency and primary care settings. As the setting becomes more specialised, the rate of stroke mimic patients falls. It is likely that clinicians in the emergency and primary care settings act as barriers or filters to stroke mimic patients reaching more acute settings.

The same process does not appear to be operating for functional disorder patients. In the identification of functional patients according to settings, there was a near reversal in prevalence rates. Stroke units identified the highest proportion of functional patients followed by mixed settings and acute stroke settings, with the lowest rates reported in emergency and ambulance settings.

It is possible that of stroke mimic conditions, functional disorders are the hardest differential diagnosis for non-specialist clinicians to make. Functional disorders, perhaps due to a lack of knowledge, or due to its perceived difficulty in correctly identifying, mean clinicians in emergency and ambulatory settings and in general practice will not risk giving this diagnosis. The secondary and tertiary clinicians however appear more confident in giving that functional disorder diagnosis.

2.4.2.2 Study design

Retrospective studies report half the rate of stroke mimic patients compared to prospective studies. These studies may be subject to a higher degree of bias than prospective studies so the higher rate of stroke mimic patients from prospective research may in fact be more accurate. Moffitt et al. (2009) reported for instance that the lifetime prevalence rate of mental disorder in prospective studies was almost double compared to the rate reported in retrospective studies.

The results reported here are similar to those in Gibson and Whiteley's (2013) review which included only prospective studies. They reported a stroke mimic rate of 26%, slightly higher than the 23.9% found in the prospective studies in this review. Their results also mirror the functional disorder rate from prospective studies. They report a functional disorder rate of 7.4% while in this study it was 8.9%.

It is unclear why the retrospective rate of functional disorder is almost double the rate reported in prospective studies. It is possible that in retrospective research, when authors were unable to give a positive differential diagnosis, they use functional diagnoses as an umbrella term for 'unknown'.

2.4.2.3 Exclusion criterion

As expected, studies which applied no exclusion criterion to their study sample reported a higher rate of stroke mimic patients than those that did. The most common exclusions were patients who did not receive thrombolysis treatment and those with incomplete data. Stroke mimic patients are less likely to receive thrombolysis and may be more likely to have incomplete data, thereby lowering the stroke mimic prevalence rate.

The rate of functional disorders was less in papers with no exclusion criteria. It is possible that studies applying exclusions to their study sample were more rigorous in their data collection methodologies and were more likely to define and count functional cases.

The discrepancy in the number of studies applying exclusion criteria (72.4% of studies) compared to those applying no criteria (25.3% of studies) makes it difficult to draw substantive conclusions here.

2.4.2.4 Countries' economic status

The incidence of stroke in low and middle income countries now exceeds the rate in high income countries (Feigin et al., 2009). The majority of studies in this review come from high income countries, likely reflecting the cost of doing this kind of research. Stratifying papers by countries' economic development may be somewhat redundant however as the wealth of a nation or their healthcare spending often does not necessarily reflect the sophistication of their healthcare system (Anderson & Frogner, 2008).

There was no difference in the rate of stroke mimic patients in high and low income countries but there was a lower rate of functional patients reported in low income countries than high income countries. This may reflect clinicians' lack of knowledge or interest in functional symptoms and patients who may be less willing to ask for or seek medical help. Little is known

about the prevalence of functional symptoms outside high-income countries (Brown & Lewis-Fernández, 2011). A paper on unexplained fatigue found it was present in all cultures but people from middle and higher income countries may be more likely to report it to their GP (Skapinakis et al., 2003).

2.4.2.5 Thrombolysis treatment

As noted in the section on exclusion criteria, whether stroke mimic patients receive thrombolytic treatment will likely affect their prevalence. When no thrombolysis was given to stroke mimic patients, the stroke mimic rate was much higher. Clinicians will apply strict diagnostic criteria when they decide to give the thrombolytic drug and will be more likely to exclude stroke mimic patients at this stage.

In studies where thrombolysis was given, the functional disorder rate was higher than in studies where it was not given. This again may reflect the fact that functional disorder is often seen as a diagnosis of exclusion rather than a disorder with positive symptoms of its own. It may be easier to exclude other types of stroke mimic patients like brain tumours from thrombolytic treatment, but in the absence of positive signs, a neurologist will likely give the treatment to a potentially functional patient rather than risk not treating a true stroke patient. There is evidence that thrombolysis is safe in patients with FND (Tsivgoulis et al., 2011), evidence that may influence doctors' treatment decision making.

2.4.2.6 Year of publication

There was no distinct pattern in the rate of stroke mimic patients over time. The rate varied between 9% and 23.2%. There were, however, an increasing number of scientific papers published since the 1980s. Given the few papers published on stroke mimic rates in the 1980s and 1990s, it is difficult to draw definitive conclusions on functional presentations to stroke wards. While the interest in stroke research increases, the rate of stroke mimic patients shows no clear pattern. This is surprising as one might expect that as diagnostic methods improve over time in all settings, there would be a subsequent reduction in the rate of stroke mimic patients.

The rate of functional patients presenting to stroke services increases minimally over time. Establishing a time trend in the prevalence and incidence of functional symptoms at all is difficult given the changes to case definitions and the rarity of studies reporting more than one rate over time. Evidence suggests that functional symptoms remain relatively stable over time. Najim (2011) found the rate of admissions of conversion disorder patients remained static over

a five year period in Iraq while earlier research by Stefanis et al. (1976) reported the rate of 'hysteria' increased over time.

2.4.2.7 Study aim

Descriptive studies reported the lowest rate of stroke mimic patients while studies with mixed aims reported the highest rate. It is worth noting however that descriptive studies were more likely to apply some kind of exclusion criteria (62%) than not (33.3%). The lower rate of stroke mimics might therefore be due to exclusion criteria rather than study design. The highest rate of stroke mimic patients was reported by studies with mixed aims, but definitive conclusions are difficult to draw as there were only three studies of this kind and the pooled prevalence of this finding has wide margins of error.

The prevalence rate of functional patients was consistent across studies with the exception of descriptive studies and service audits where the rate was almost double.

2.4.2.8 Quality scores

The average quality score for studies was high but analysis of quality scores by stroke mimic and functional disorder prevalence showed no clear pattern.

2.4.3 Limitations

It is likely that the rate of functional disorder reported in this study is an underestimate. It is possible that clinical staff who assess newly referred patients may avoid giving a functional diagnosis completely or use other terminology, like migraine or 'functional overlay' to avoid potentially uncomfortable discussions with patients. Such a bias is likely to affect each setting, from emergency settings through to tertiary stroke care. We have attempted to address this by demonstrating that papers that do not list functional disorders have inflated numbers in their 'other' categories compared to studies which list functional disorder rates, a result which is strongly suggestive that a proportion of functional cases are hidden within the 'other' category.

The stroke mimic rate varied widely. This may be partly explained by the variety of ways in which stroke mimic patients were defined. Commonly, no information was given on how stroke mimic patients were defined. Where information was available, some studies used a prospective medical follow-up by the clinical team or used the presence of an alternative diagnosis to indicate stroke mimic status. Other papers applied less stringent definitions relying only on a lack of positive findings from imaging results, counting stroke mimic patients as any patients with a 'non-cerebrovascular event' or classifying them as 'no acute stroke

found'. The multiplicity of stroke mimic definitions precluded the possibility of investigating their effect on our stroke mimic event rate.

With the exception of Gargalas et al.'s (2015) paper, whose aim was specifically to quantify the functional mimic rate, papers included in this review were often unclear or vague regarding the functional disorder definitions they employed and none used structured interviews to make the diagnosis. Diagnoses were made by stroke clinicians, general practitioners (GPs) or emergency personnel. Some papers, like Ferro et al. (1998), used multiple terms to describe patients that in other studies were classed as one disorder but did not explain the differences in diagnoses employed.

This review counted only the most frequent stroke mimic diagnosis from each study but did not count the total number of stroke mimic diagnoses from all studies. Given the 14,708 stroke mimic patients included with a potentially extensive number of stroke mimic diagnoses, this was beyond the remit of this paper, but may be a useful analysis in future research.

Finally, there was a high level of statistical heterogeneity across studies. Due to the very little existing evidence on functional stroke patients, this review applied minimal exclusion criteria. While Gibson and Whiteley's (2013) paper restricted their analysis to only prospective studies, papers in our review were not restricted by studies' methods, design or quality. We attempted to account for heterogeneity by conducting comprehensive stratified analyses but such analyses can only go so far. It is likely that different services see different types of patients due to a large variety of reasons such as the expertise of clinicians within certain services or macro-level differences like health insurance systems within different countries. Such processes may affect the prevalence of functional patients and stroke mimic patients but are difficult to measure and account for.

2.4.4 Conclusions

This review is the first of its kind to explore the rate of functional disorders and its associated demographic and symptom features in stroke settings. While many studies focus on the rate of stroke mimic patients, fewer have examined functional disorder patients in particular, and fewer again give information on their demographic or clinical features.

Functional disorders may be the 'Cinderella' of stroke services. The disorder consistently appears as a differential stroke diagnosis but there are currently no protocols in the UK on how to effectively diagnose, treat or refer functional patients who appear within stroke settings. The lack of such information in this area is conspicuous.

Chapter Three: A qualitative study of stroke clinicians' experiences treating stroke mimic patients in a hyper acute stroke setting

3.1 Introduction

Patients with functional disorders consistently present as stroke mimic patients across a range of stroke settings. Chapter Two established that functional disorder patients account for 11.8% (95% CI: 9.3 – 14.9%) of stroke mimic admissions to acute stroke wards. These patients are more often female and younger than medical mimics and they most commonly present with weakness.

What happens once a functional patient is admitted to an acute ward is less well known. This and the following chapter investigate functional disorder admissions from clinicians' and patients' perspectives. This chapter adopts a mixed methods approach to assess clinicians' experiences and attitudes towards functional patients in the hyper acute stroke setting. Clinicians' views are themselves important as they can directly affect the outcomes of patients.

Doctor-patient relationships can be fraught and this may be especially so in the case of functional patients. Clinicians and functional patients alike can find interactions both unsatisfactory and stressful and encounters can be characterised by misunderstandings and mutual distrust (Kenny, 2004). Medical consultations with patients with unexplained symptoms are associated with more unmet expectations, higher healthcare costs and higher patient dissatisfaction (Jackson & Kroenke, 1999). Research from primary care with patients with medically unexplained symptoms however found that if the first clinical encounter is positive, it is associated with fewer subsequent visits (Owens et al., 1995).

Much of the research on doctor-patient interactions comes from primary care but it is likely that clinicians' attitudes towards patients with unexplained symptoms in acute settings, may be more challenging and complex given the occupational pressures of working in these settings. The emergency department, general medical wards and intensive care units are demanding environments where staff may lack the time and resources to meet the needs of patients with specific mental health requirements (van der Kluit & Goossens, 2011). Evidence suggests some clinicians view functional patients as illegitimate recipients of care (Kirmayer et al., 1994) or as blocking beds for patients with physical disease. Consequently, functional patients may distrust physicians and believe their needs are not being met.

3.1.1 Clinicians' attitudes to unexplained syndromes

Doctors and nurses in medical settings have described working with mental health patients as challenging. Medical staff in acute settings can feel a lack of positive reinforcement, a lack of institutional support, and believe that mental health patients should not be in acute settings at

all (Bailey, 1998). Foundation-year and trainee doctors have been shown to hold attitudes towards mental health patients on par with those held towards criminal populations (Noblett et al., 2015). Consultations with patients with unexplained symptoms have been described as a place of contest and likened to a 'court of law, a medieval siege, a tug of war' (Marchant-Haycox & Salmon, 1997) or a 'duet of escalating antagonism' (Kleinmann, 1988).

Clinicians' attitudes form early in their careers and negative attitudes can extend to mental health professionals. Medical students can hold discriminatory views on the psychiatry profession and have been described believing psychiatrists have "a tendency to over-conceptualise" (Nielsen & Eaton, 1981). When asked to compare psychiatrists to surgeons, physicians, and GPs, students believed psychiatrists were "confused thinkers" (Harris, 1981) and their patients were "not easy to like" (Wilkinson et al., 1983). A survey of medical students showed they hold the highest regard for pneumonia patients and the lowest for patients with long-standing, unexplained abdominal complaints (Korszun et al., 2012).

These attitudes continue, even as careers develop and experience grows. Hartz et al. (2000) reported only 14% of GPs described 'very good' or 'excellent' satisfaction in managing unexplained symptoms. In an attitudinal study of neuroscience nurses in a neurology unit, Ahern et al. (2009) found 46% of nurses believed functional disorder patients were 'manipulative'. GPs described consultations with functional patients as 'frustrating', referring to them as 'heart-sink' patients (Wileman et al., 2002). In one survey, 44% of neurologists believed there was an overlap in the relationship between conversion disorder and feigning symptoms (Kanaan et al., 2011).

Such negative views could be fostered and maintained by mechanisms like stereotyped thinking, a lack of interest, negative symptom attributions, poor mental health knowledge, a lack of belief in their own competence and incompatible perspectives between clinicians and patients when treating symptoms.

Previous qualitative research found some GPs had a tendency to stereotype functional patients as having 'undesirable traits' and often believed they failed to conform to society's work ethic (Raine et al., 2004). The stereotyping of patients can mean their condition becomes their defining characteristic. In surgery settings it was found nurses adopted a 'risk attitude' when looking after mental health patients and many held stereotyped perceptions such as a belief in their non-compliance to medical advice (MacNeela et al., 2012).

A lack of interest in functional disorders may perpetuate attitudes. When compared to other patients with a clear somatic diagnosis, physiotherapists were found to have only a moderate interest in treating these patients (Edwards et al., 2012).

Clinicians can feel like they have failed if they don't find an organic cause for a presenting complaint. In a series of interviews with GPs in Iowa, 17% reported finding organic causes was their primary aim (Nordin et al., 2006). Potentially missing an organic cause can be worrying, but might also affect a clinician's career. Doctors may also feel dissatisfied if they are unable to treat underlying functional symptoms. Ahern et al.'s (2009) study of neuroscience nurses found 75% of respondents believed their knowledge of functional symptoms was limited and clinicians have reported believing treatment for these patients to be pointless (Salmon et al., 2007).

Feeling incompetent may undermine professional identity and as a consequence clinicians might feel insecure or powerless (Woivalin et al., 2004). Nurses with mental health knowledge have a more positive attitude towards patients with comorbid mental health problems compared to those without such knowledge (Mavundla, 2000) and nurses with more professional experience generally had a more positive attitude towards these patients (Bjorkman et al., 2008). A large survey of UK medical schools examining the reasons doctors rejected psychiatry as a profession found it could be partly explained by trainees' self-appraisal of their own occupational competence (Lambert et al., 2003). This may reflect a wider, endemic problem. For instance, a lack of managerial support for general ward nurses caring for mental health patients has been reported and many believed they lacked appropriate clinical supervision (Harrison & Zohhadi, 2005). Managerial and structured support in how to manage patients with mental health problems or functional symptoms might help reduce beliefs of professional ineffectiveness.

Engaging with patients' psychological motivations and personal experiences may be an activity some clinicians wish to avoid. GPs have been found to respond to patients with medically unexplained symptoms by trying to normalise their symptoms, providing reassurance, but they tend not to engage with their individual concerns (Fitzpatrick, 1996), even when patients give cues to their psychosocial problems (Ring et al., 2005). GPs are more likely to offer medical care like drugs, physical investigations and specialist referral to patients who do not discuss psychosocial difficulties (Salmon et al., 2006). Doctors have also been found to decline 'empathic opportunities' and are less likely to explore the concerns of medically unexplained patients (Epstein et al., 2006). In contrast, research has shown patients want more emotional support from their clinicians and most will openly discuss their psychological symptoms if asked (Peters et al., 1998).

Olde Hartman et al. (2009) argue that clinicians' inability to engage with psychological symptoms comes from a lack of common epistemological understanding between clinicians and patients. If patients and doctors do not share the same views on what causes symptoms,

these divisions can lead to the direct dissolution of the doctor-patient relationship. Asbring and Narvanen (2003) argue there is an incongruence between the objective methods of diagnosis and treatment taught in medical school and the realities of treating illness and distress within their social context, leaving many new doctors unprepared. Physicians are trained to refer to visible findings and test results while patients claim authority in the understanding of their own body and pain (Rhodes et al., 1999; Peters et al., 1998). Such incongruence in thinking can lead to contested diagnosis and conflict.

Patients are not immune to clinicians' attitudes and as a consequence of poor interactions, may become more entrenched in their idiosyncratic health beliefs. Negative emotions, like frustration, can be shared and escalate. This has been named the 'looping effect' where cycles of emotions worsen when a patient's emotional response triggers and heightens emotions in the clinician (Kirmayer & Sartorius, 2007).

How receptive the doctor views the patient to be to their guidance may play an important role. For many clinicians, it is important that the patient has insight into the nature of their own symptoms, is willing to share responsibility for their management (Nordin et al., 2006) and does not undermine the opinion of the doctor or lack trust in their abilities (Wileman, 2002). A large postal survey of 349 neurologists found that they were willing to discuss the psychological factors involved in functional disorder once they believed the patient was receptive to such a discussion (Kanaan et al. 2011).

Contested authority and struggles for control often mark these medical consultations. As paternalistic models of doctor-patient relationships lose favour and non-hierarchical doctor-patient interactions are advocated (Mead & Bower, 2000), clinician-patient relationships may improve. Reaching a shared understanding of the cause and treatment of symptoms is the first step in improving the relationship. Possible methods of improvement include encouraging patients to become an active participant in their own care, to voice their ideas while clinicians listen, reflect and offer collaboration.

3.1.2 Improving the doctor-patient relationship

A number of interventions have been proposed to improve the clinician-patient relationship to help improve attitudes to mental health patients generally.

Working in mental health as an undergraduate medic is effective in fostering a positive attitude to psychiatry (Singh et al., 1998). A qualitative analysis of scientific and narrative reviews on positive consultations with patients with unexplained symptoms highlighted the importance of non-specific factors like improved communication, the creation of a safe

therapeutic environment and the importance of giving reassurance and regularly scheduled appointments (Heijmans, 2011).

Patients with medically unexplained symptoms found the most helpful explanations from clinicians were those that encouraged them to feel control over their symptoms (Salmon et al., 1999). Other positive steps include taking a careful history at the first assessment, probing for recent stressors, completing physical examinations (Sharpe, 2002), giving positive explanations, indicating to patients that they believe the patient, emphasising the high prevalence of functional symptoms generally, and where appropriate, making psychiatric referrals (Stone, Carson, & Sharpe, 2005).

There is evidence that formal training can improve clinicians' attitudes. A trial testing a cognitive-oriented educational programme improved GPs' attitudes towards patients with somatisation (Rosendal, 2005). Reattribution training where clinicians are taught how to provide psychological explanations to patients with medically unexplained symptoms also found improvements in doctor-patient communication (Morriss et al., 2007). An earlier study by the same authors found positive patient improvements when GPs were taught how to encourage patients to relate physical symptoms to psychosocial causes (Morriss et al., 1999).

Interventions can improve the doctor-patient relationship but understanding attitudes and experiences within their clinical context is the first step in this process.

3.1.3 Aim of research

Much of the existing evidence on doctor-patient relationships comes from primary care. GPs have more time to develop relationships with their patients yet the majority find patients with unexplained symptoms difficult to manage (Reid et al., 2001). The time constraints and pressurised nature of acute care likely mean relationships between doctors and patients in acute settings are even more strained. There is little evidence on the experiences of clinicians in specialised, tertiary care settings with patients with functional diagnoses, and there is no existing research on stroke staffs' attitudes to functional stroke patients.

This study aimed to investigate and describe the attitudes, opinions and experiences of hyper acute stroke clinicians towards FND patients through the use of a large survey of hyper acute stroke settings in England and a series of semi-structured interviews with staff in one HASU. Stroke staff's views on the potential treatment and referral options for FND patients were also examined.

3.2 Methods

The first half of this section outlines the methods used to conduct the survey study. The second section outlines the methods used to conduct semi-structured qualitative interviews with stroke staff at one HASU site.

3.2.1 Survey procedure

Multi-disciplinary teams from twelve stroke settings were surveyed, eleven of which were HASUs and one was a stroke ward. The stroke ward was included as a comparator but due to the low response rate at this site, statistical comparisons were unfeasible.

A snowball sampling method was chosen. Questionnaires were given to a manager or senior clinician in each stroke team. They were asked to distribute questionnaires to other stroke staff members. Most frequently, this person was the multidisciplinary teams' lead such as the nurse consultant. At two settings the researcher attended multidisciplinary meetings in person and distributed questionnaires. See Table 4 for a list of the sites contacted for involvement and their response rates.

Table 4 NHS stroke services participating in the survey

Stroke sites	n (%)
Salford Royal	25 (20.4)
Northwick Park	17 (13.9)
Northumbria Emergency Specialist Hospital	14 (11.5)
King's College Hospital	13 (10.7)
Barts and the London	12 (9.8)
Southampton General Hospital	12 (9.8)
St Georges	8 (6.6)
Princess Royal University Hospital	6 (4.9)
University College London Hospital	5 (4.1)
Charing Cross Hospital	5 (4.1)
Royal Hampshire County Hospital	3 (2.5)
St Thomas' (stroke ward)	2 (1.6)
Total	122 (100)

Any stroke clinician who had experience with functional stroke mimic patients was invited to complete the questionnaire. No exclusion criteria were applied to any staff members but some decided that they did not have enough experience to warrant involvement and self-excluded. The snowball sampling method employed in this study meant a non-response rate could not be ascertained.

All questionnaires, both paper and electronic versions are stored in accordance with the Data Protection Act of 1998.

3.2.2 Questionnaire

Questionnaires were derived from a template used by Reid et al. (2001). These authors developed and piloted the questionnaire with a panel of GPs and it was designed to illicit GPs' attitudes to patients with medically unexplained symptoms. Questions were adapted for stroke staff.

All questionnaires were anonymous. Information on participants' age, gender, speciality and grade was collected. Information was collected on participants' attitudes to patients with functional stroke symptoms and treatment as well as views on their role in the management of the functional stroke patients. Questionnaires asked which setting functional stroke patients should be managed in and which setting currently provided the most effective management of patients. Additional questions, not in Reid et al.'s study, on clinicians' attitudes to research in the area of functional symptoms and their view on guidelines were also collected.

There were eleven survey questions, eight of which required participants to respond on a four-point Likert scale from "strongly agree", "agree", "disagree" or "strongly disagree" to questions designed to elicit clinicians' attitudes towards patients with functional stroke symptoms, where they believed patients should be treated and their view on the use of physiotherapy for this group.

Staff were given no incentive in exchange for completing the questionnaire.

The questionnaire was piloted at a research meeting of neuropsychiatrists at King's College London on 16th February 2016. Participants completed the questionnaire and provided feedback which was incorporated into the questionnaire. The survey was distributed to HASUs by hand between February and November 2016. See "Appendix 3.2: Stroke staff questionnaire" for a copy of the questionnaire used.

3.2.3 Survey analysis

Statistical analysis was completed using SPSS (IBM SPSS for Windows, Version 22, Chicago, SPSS Inc.). Survey responses were re-coded from 'strongly agree' or 'agree' into one 'agree' category and the responses 'strongly disagree' or 'disagree' were re-coded into a 'disagree' category. Frequencies were used to compare differences between groups and where appropriate, chi-square tests were used to assess differences in response proportions.

3.2.4 Qualitative study

3.2.4.1 Qualitative study: setting

The qualitative study took place at one HASU in London. The researcher was embedded at this site from 18th January 2016 until 19th October 2016 (with the exception of weekends and public holidays).

As outlined in Chapter Two, HASUs are designed to provide rapid assessment and early treatment to stroke patients. They are open twenty-four hours a day. The ward is staffed by six consultants who work on rotation, each working four weeks at a time. There are three specialist registrars attached to the unit who share responsibility for both the outpatient clinics and the inpatient ward. The ward is also staffed by multidisciplinary clinicians who include specialist nurses, occupational therapists, dieticians and physiotherapists. The HASU also employs a neuropsychologist who meets patients if any psychological issues arise. Occasionally a patient with functional symptoms will be meet the psychologist on the ward.

3.2.4.2 Qualitative study: procedure

The semi-structured interview script was developed in partnership with the study's chief investigator.

Staff members at the HASU were contacted and asked if they would like to participate in an interview. No staff member who was approached refused to participate. Recruitment was purposive to ensure gender and job specialities were representative. The HASU's clinical neuropsychologist was not interviewed. Although they would have been useful in the kind of psychological insights they could give, this clinician was aware of the study and partially contributed to its design.

There was no monetary payment for participation but participants were given a box of chocolate after the interview as a gesture of gratitude. Interviews were held in a private office on the HASU ward at a time of participants' choosing and were conducted in private.

Participants were given the study's information sheet (see "Appendix 3.3: Information sheet for NHS staff") and information about the study was also given verbally. Participants were asked to sign the consent form prior to their participation (see "Appendix 3.4: Consent form for NHS staff").

At the start of each interview, as a way of introduction, each interviewee was told that the interviews would discuss functional stroke patients' presentations to the HASU. It was explained that for the purposes of the interview, functional stroke symptoms were regarded as

a type of stroke mimic presentation whereby there was no medical explanation for the symptoms presented and that these patients could be distinguished from another type of stroke mimic, namely 'medical mimics' where there was a medical explanation for the symptoms. The interviewer did not mention the role that psychological processes may or may not play in symptom presentation as this was a topic to be elicited in the interview itself.

See "Appendix 3.5: Interview schedule for NHS stroke staff" for the semi-structured interview schedule used.

3.2.4.3 Qualitative study: analysis

Interviews were analysed using thematic analysis which allows for the identification, classification and organisation of themes (Braun & Clarke, 2006). Unlike Grounded Theory (Glaser et al., 1968) or Discourse Analysis (Foucault, 1972), thematic analysis is atheoretical. Themes within thematic analysis are considered to capture something important about the data.

There is debate regarding the type of quality criteria which can and should be applied to qualitative research. The traditional concepts of reliability, validity and objectivity are often rejected, with the argument that unlike quantitative research, qualitative studies rely on non-numerical information and phenomenological interpretation, therefore requiring different quality checks (Leung, 2015).

Qualitative researchers have instead proposed alternative concepts to assess quality such as consistency, neutrality, confirmability, applicability, credibility, coherence, generalisability, trustworthiness and authenticity (Guba, 1989; Lincoln & Guba, 1985; Noble, 2015). As theoretical terms have developed, there has been a drive to develop quality checklists such as the NICE quality guidelines (NICE, 2012). Checklists recommend techniques like purposive sampling, grounded theory, triangulation, and respondent validation.

The reliance on such checklists has been criticised as counterproductive in that they can reduce qualitative research to a list of prescriptive technical procedures which in themselves do not confer rigour (Barbour, 2001). These checklists can be useful as frameworks by which to guide the research. In this study, three approaches were adopted to help enable methodological rigour.

Firstly, to enable a reflexive approach, the researcher kept a field diary on each day of the study where observations on the ward and the researcher's experience interviewing participants were recorded. This approach helps foster critical self-reflection (Ortlipp, 2008). In addition, the participant was based on the HASU for ten months and immersion in the culture

of the ward helped enable a broader understanding of the processes at play as prolonged involvement in the community of interest may enhance sensitivity and validity (Kirk & Miller, 1986).

Secondly, all interviews were recorded using a Dictaphone. The researcher transcribed all interviews. This helped improve familiarity with the data. Names and any identifying information such as place or person's names were removed from transcripts. Transcripts can provide a good record of naturally occurring interactions and are a reliable record of those interactions (Seale & Silverman, 1997).

Finally, all transcripts were read, re-read and analysed using thematic analysis and the qualitative programme ATLAS.ti (version 7.5.12, Berlin, Scientific Software Development). Using qualitative software packages has been welcomed as an important development in improving rigour (Pope et al., 2000). Transcripts were coded by labelling each line of dialogue with a basic descriptive code.

Throughout the analysis an iterative process took place with codes added, removed, merged or split. Each line of data was given a code which formed a coding framework. This coding framework was made up of one hundred and ten codes. All codes were grouped into 'thematic families'. These families represent clusters of similar issues. Thematic families were then further grouped into four 'global themes'.

3.2.4.4 Qualitative study: ethical considerations

Ethical approval was granted by the Queen Square Research Ethics Committee (REC) (15/LO/1914) on the 6th January 2016 and local research and development (R&D) approval was received on the 15th January 2016. The study received approval from the hospital site's Neurosciences Research and Advisory Group (RAG) on the 13th January 2016.

The main ethical concerns in this study were the maintenance of privacy and confidentiality. Due to the relatively small size of the HASU team, and the potentially sensitive nature of the interviews, it was important that staff interviews were conducted in private and all information was confidential. All data collected from the qualitative interviews, both audio and transcript materials were stored under the Data Protection Act of 1998. Only the research team alone had access to de-identified information which was kept in a locked drawer or in its electronic form, with an electronic password.

3.3 Results

3.3.1 Survey results

3.3.1.1 Participants

In total, 122 questionnaires were returned. Across the twelve sites, the mean number of completed surveys was 10.3 (SD: 6.4). Of survey respondents, the most common occupation type was physiotherapy (*n* = 27).

Additionally, 15 stroke consultant doctors completed the survey, twelve junior doctors, sixteen occupational therapists, seven neurologists and eight nurses. Twenty-two respondents did not state their job titles (see Table 5).

Six participants did not give information on their gender. Of those who did, 87 were women (75%) and 29 were men (25%).

The mean age was 34.5 years (SD: 9.1, range 22 – 61). When age and gender were explored according to participants' occupation, all occupational therapists were women and the lowest proportion of female respondents was amongst stroke consultants (33.3%). Stroke consultants were on average the eldest participants (mean age 46.7, SD: 8.6) while occupational therapists were the youngest (mean age 30.8, SD: 7.8).

Table 5 Survey participants according to profession, age and gender

Profession	Respondents n (%)	Mean age (SD)	Female n (%)
Physiotherapist	27 (22.1)	31 (5.2)	21 (77.8)
OT	16 (13.1)	30.8 (7.8)	16 (100)
Consultant	15 (12.3)	46.7 (8.6)	5 (33.3)
Junior doctor	12 (9.8)	31.7 (5.5)	8 (66.7)
Neurologist	7 (5.7)	31.3 (3)	6 (85.7)
Nurse	8 (6.6)	32 (4.7)	6 (75)
Other[1]	15 (12.3)	36.2 (12.2)	11 (73.3)
Not stated	22 (18)	38.3 (9.2)	14 (63.6)
Total	122 (100)	34.5 (9.1)	87 (75)[2]

[1]'Other' category includes therapy assistants, clinical psychologists, speech and language therapists, neuroscientists and allied health professionals
[2]Six participants did not report their gender
OT = Occupational therapist

3.3.1.2 Survey results: attitudes to functional patients

The frequency of agreement to statements related to the possible cause of functional stroke symptoms and clinicians' belief of how easy or not these patients are to manage was analysed (see Table 6).

Respondents were more likely to agree or strongly agree that patients with functional stroke symptoms are "difficult to manage" (77.9% agreed with this statement). Most respondents (75.4%) disagreed or strongly disagreed that patients with functional stroke symptoms have an undiagnosed physical illness. Participants were also more likely to disagree that patients with functional stroke symptoms have a personality disorder (69.7% disagreed). There was no difference between the rate of respondents agreeing and disagreeing with the statement that 'patients with functional stroke symptoms have a psychiatric illness' (54.1% disagreed).

Table 6 Table displaying agreement to statements on patients with functional stroke symptoms

Patients with functional stroke symptoms are:	Agree & strongly agree n (%)	Disagree & strongly disagree n (%)	Missing n (%)	*p* value
"Difficult to manage"[a]	95 (77.9)	26 (21.3)	1 (0.8)	**0.001**
"Have an undiagnosed physical illness"[a]	23 (18.9)	92 (75.4)	7 (5.7)	**0.001**
"Have personality disorders"[a]	34 (27.9)	85 (69.7)	3 (2.5)	**0.001**
"Have a psychiatric illness"[a]	53 (43.4)	66 (54.1)	3 (2.5)	> 0.05

[a] Chi-square test comparing 'agree or strongly agree' with 'disagree or strongly disagree' rates

Agreement and disagreement to these statements were assessed according to profession, gender and age profile. Age was transformed from an integer into a categorical variable and organised by decade (see Table 7).

Table 7 Table displaying frequency of 'agree' or 'strongly agree' responses to statements by profession, age and gender

	"Patients with functional symptoms are difficult to manage" n (%)	"Patients with functional stroke symptoms have an undiagnosed physical illness" n (%)	"Patients with functional stroke symptoms have personality disorders" n (%)	"Patients with functional stroke symptoms have a psychiatric illness" n (%)
Overall	95 (77.9)	23 (18.9)	34 (27.9)	53 (43.4)
Profession				
Consultant	12 (80)	3 (20)	6 (40)	8 (53.3)
Junior doctor	10 (83.3)	3 (25)	3 (25)	3 (25)
Neurologist	7 (100)	0 (0)	1 (14.3)	2 (28.6)
Nurse	5 (62.5)	3 (37.5)	4 (50)	2 (25)
OT	13 (81.3)	3 (18.8)	4 (25)	12 (75)
Other	9 (60)	3 (20)	1 (6.7)	4 (26.7)
Physiotherapist	23 (85.2)	5 (18.5)	7 (25.9)	13 (48.1)
Unknown	16 (72.7)	3 (13.6)	8 (36.4)	9 (40.9)
Gender				
Female	69 (79.3)	17 (19.5)	24 (27.6)	39 (44.8)
Male	23 (79.3)	6 (20.7)	8 (27.6)	13 (44.8)
Age				
21-30	28 (77.8)	5 (13.5)	5 (13.5)	17 (45.9)
31-40	35 (83.3)	10 (23.8)	14 (34.1)	20 (47.6)
41-50	7 (87.5)	2 (25)	1 (12.5)	3 (37.5)
51-60	8 (88.9)	1 (12.5)	3 (37.5)	2 (22.2)
61-70	1 (100)	0 (0)	0 (0)	1 (100)

In response to the statement "Patients with functional symptoms are difficult to manage", the professions displaying the most frequent agreement were neurologists followed by physiotherapists. The profession least likely to agree were those grouped in the 'other category'.

In response to the statement, "Patients with functional stroke symptoms have an undiagnosed physical illness", neurologists were most likely to disagree while 37.5% of nurses agreed or strongly agreed with the statement.

In response to the statement, "Patients with functional stroke symptoms have personality disorders", there were consistently low rates of agreement, with the 'Other' category and neurologists most likely to disagree and the highest rate of agreement amongst nurses and stroke consultants. Fifty per cent of nurses surveyed agreed with the statement although the total number of nurses responding to this statement was only eight.

In response to the statement, "Patients with functional stroke symptoms have a psychiatric illness" there was a varied response. Of all professions, occupational therapists most

frequently agreed with the statement and the profession most likely to disagree were junior doctors and nurses.

There was no statistical difference in agreement to any statement according to age.

3.3.1.3 Survey results: attitudes to treatment

In response to the statement, "Patients with functional symptoms should be managed in…", the majority of participants said primary care (32.8%), mental health settings (27.9%) and 'other settings' (27%).

In response to the question, "Which setting currently provides the most effective treatment for patients with functional stroke symptoms?", the majority of respondents again chose primary care (44%), followed by 'other settings' (24.6%). The lowest proportion of participants chose 'outside the NHS' for both statements. Response rates are outlined in Table 8.

Table 8 Breakdown of responses on where functional stroke patients should be managed and which setting provides the most effective treatment

	"Patients with functional stroke symptoms should be managed in" n (%)	"Which setting currently provides the most effective treatment for patients with functional stroke symptoms?" n (%)
Primary care	40 (32.8)	54 (44.3)
Medical/surgical outpatients	9 (7.4)	11 (9)
Mental Health	34 (27.9)	19 (15.6)
Outside the NHS	1 (0.8)	2 (1.6)
Other settings	33 (27)	30 (24.6)
No response	5 (4.1)	6 (4.9)
Total	122 (100)	122 (100)

Participants were asked "What is the role of the doctor or health care team in managing functional stroke symptoms?" and were asked to select up to three responses. The responses chosen most frequently were "To provide reassurance and support" (34.5%), "To provide counselling and appropriate psychological management" (30.7%) and "To act as a gatekeeper preventing inappropriate investigation" (19.1%). No respondent agreed with the statement that their role was "To prescribe psychotropic medication" or "To have no involvement at all". Response rates are outlined in Table 9.

Table 9 The rate of agreement to statements regarding the doctor or health care team's role in managing functional stroke symptoms. Participants could choose up to three.

"What is the role of the doctor or health care team in managing functional stroke symptoms?"	n (%)
"To provide reassurance and support"	110 (34.5)
"To provide counselling and appropriate psychological management"	98 (30.7)
"To act as a gatekeeper preventing inappropriate investigation"	61 (19.1)
"To refer for further investigations to identify a cause"	46 (14.4)
"Not to get too involved in their management"	4 (1.3)
"To prescribe psychotropic medication"	0 (0)
"To have no involvement with them at all"	0 (0)
Total	319 (100)

3.3.1.4 Survey results: attitudes to further research in the area

The majority of respondents (95.8%) agreed or strongly agreed with the statement that further research is needed in the area of functional stroke symptoms. Answers were evenly divided in response to the statement: "There are effective treatments for functional stroke patients" with 50.9% of respondents agreeing with the statement. The majority of respondents (83.9%) agreed or strongly agreed that "Physiotherapy could prove an effective treatment for some functional stroke patients" and 89.9% of respondents disagreed or strongly disagreed with the statement "There are clear guidelines on how to manage patients with functional stroke symptoms". Responses are outlined in Table 10 below.

Table 10 The frequency of responses to survey statements on research and treatments for functional stroke patients

	Strongly agree or agree n (%)	Strongly disagree or disagree n (%)	Missing n (%)
"Further research is needed into the area of functional stroke symptoms"	115 (95.8)	5 (4.2)	2 (1.6)
"There are effective treatments for functional stroke patients"	59 (50.9)	57 (49.1)	6 (4.9)
"Physiotherapy could prove an effective treatment for some functional stroke patients"	99 (83.9)	19 (16.1)	4 (3.3)
"There are clear guidelines on how to manage patients with functional stroke symptoms"	12 (10.2)	106 (89.9)	4 (3.3)

Responses were compared according to profession, age and gender categories. A Chi-square test found no statistically significant difference between men or women's responses to any of the four statements.

When examined by profession, all consultants, junior doctors, neurologists and physiotherapists agreed or strongly agreed that, "Further research is needed into the area of functional stroke symptoms".

In response to the statement, "There are effective treatments for functional stroke patients" there was a more varied response pattern. The profession most frequently agreeing or strongly agreeing with this statement were neurologists. The professional group which was least likely to agree or strongly agree with the statement were consultants at 40%.

In response to the statement "Physiotherapy could prove an effective treatment for some functional stroke patients", all consultants and neurologists agreed or strongly agreed with the statement. The professional groups agreeing least with this statement were nurses and the 'Other' group at 66.7%.

Agreement to the statement, "There are clear guidelines on how to manage patients with functional stroke symptoms", no neurologist or profession labelled 'other' agreed. Agreement to this statement was low across all professions with the highest rate of agreement amongst neurologists at 100%. Table 11 displays agreement to statements regarding treatment by profession type. There was no significant difference in responses with regards age or gender.

Table 11 Table displaying percentage of 'strongly agree' or 'agree' responses to statements regarding treatment and research by profession, age and gender

	"Further research is needed into the area of functional stroke symptoms" n (%)	"There are effective treatments for functional stroke patients" n (%)	"Physiotherapy could prove an effective treatment for some functional stroke patients" n (%)	"There are clear guidelines on how to manage patients with functional stroke symptoms" n (%)
Overall	115 (95.8)	59 (50.9)	99 (83.9)	12 (10.2)
Profession				
Consultant	15 (100)	6 (40)	14 (100)	1 (6.7)
Junior doctor	12 (100)	5 (41.7)	11 (91.7)	1 (9.1)
Neurologist	7 (100)	5 (71.4)	7 (100)	7 (100)
Nurse	6 (85.7)	4 (57.1)	4 (66.7)	1 (14.3)
OT	15 (93.8)	9 (56.3)	15 (93.8)	2 (12.5)
Other	14 (93.3)	7 (50)	10 (66.7)	14 (100)
Physiotherapist	27 (100)	13 (54.2)	24 (88.9)	3 (11.5)
Unknown	19 (90.5)	10 (47.6)	14 (66.7)	4 (18.2)
Gender				
Female	81 (95.3)	40 (49.4)	72 (84.7)	8 (9.6)
Male	29 (100)	14 (48.3)	22 (81.5)	4 (13.8)
Age				
21-30	35 (94.6)	18 (51.4)	30 (81.1)	4 (11.4)
31-40	42 (100)	21 (51.2)	37 (92.5)	4 (9.5)
41-50	7 (87.5)	5 (71.4)	6 (75)	1 (12.5)
51-60	9 (100)	4 (50)	7 (77.8)	2 (25)
61-80	1 (100)	1 (100)	1 (100)	0 (0)

Some participants wrote additional comments on the paper survey. These were collected and are outlined in Table 81 – Table 90, (see "Appendix 3.1: Qualitative survey responses).

3.3.2 Qualitative results

3.3.2.1 Participants

In total, 14 staff members were recruited to the qualitative study. Seven female and seven male staff members were interviewed. Five senior house officers, three nurses (one nurse manager, one TIA nurse specialist and one nurse consultant), one physiotherapist, two neurology registrars, two stroke registrars, and one geriatrics registrar were interviewed.

The average length of interviews was 25 mins 43 secs (range: 16 – 41 minutes). See Table 12 for a list of the clinical staff interviewed according to profession, ethnicity and gender. Age information was not collected.

Table 12 List of qualitative interviewees

Position	Ethnicity	Gender
Senior house officer	Mexican	Female
Senior house officer	Romanian	Female
Locum senior house officer	White British	Male
Nurse	Black British	Male
Physiotherapist	White British	Male
Registrar	British other	Male
Senior house officer	Singaporean	Male
Senior house officer	Other	Female
Geriatrics registrar	White British	Female
TIA/thrombolysis nurse specialist	Black British	Female
Neurology registrar	British other	Male
Neurology registrar	White British	Male
Registrar	White British	Female
Nurse consultant	White British	Female

In total, 110 were created from the interview data. These codes were grouped into 'thematic families' which were then grouped by 'global themes'. Global themes and their constituent thematic families are outlined in Table 13.

Table 13 Table outlining the themes from qualitative staff interviews and their constituent thematic families

	Global Themes			
	'Symptom attributions'	'Interactions with patients'	'Clinical responsibility'	'Systemic pressures'
Thematic families	Conscious v unconscious	Diagnostic labels	Prioritisation	Need for beds
	Secondary gain	Obfuscation	Managing risk and uncertainty	Staff shortages
	Anxiety	Metaphor	Treatment and referral	
	Feigning	Diagnostic methods	Professional differences	
	Neurological complexity		Professional hierarchies	

The following sections outline the results of the interviews according to the four main global themes identified.

3.3.2.2 Symptom attributions

This section explores staff members' illness attributions towards patients with functional stroke symptoms. Attribution theory attempts to explain how people understand the causes of events and behaviour (Weiner, 1980). An external attribution will link the cause of an event to an external source; for example a traumatic life event. Internal attributions are those where cause is ascribed an internal characteristic, for instance linking depression to personality traits. There is evidence that when people attribute mental health symptoms in others to mechanisms beyond that person's control they will display more acceptance and tolerance and be less likely to blame the person for their symptoms (Corrigan et al., 2001).

Some research suggests a belief in stress or anxiety as a causal factor is associated with greater tolerance (Schnittker, 2008). Psychosocial attributions like abuse can help reduce the perception of personal responsibility but may increase the sense of otherness, 'them' versus 'us' (Schomerus, 2014). Attributions can vary depending on clinicians' speciality. A study on clinicians' beliefs on the cause of 'Gulf War Illness' found internal medicine clinicians were more likely to believe mental health problems or stress was the cause of the problem while mental health clinicians attributed the illness to viruses, bacteria and exposure to toxins (Richardson et al., 2001). Gaining insight into clinicians' attributions may therefore help predict attitudes and behaviour.

In these interviews, two attribution types emerged. The first aligned with current psychological models of functional symptoms where cause was seen as complex and multi-dimensional. A second attribution type emerged where clinicians saw symptoms as volitional and where they

ascribed blame to the individual patient. Such attributions may reflect stereotyped thinking and emotional responses to occupational pressures as well as genuine uncertainty as to the role of volition in functional disorders.

All staff members were asked directly what they believed caused patients' functional symptoms but, in many instances, attributions emerged unprompted such as anxiety, interpersonal conflict, pre-existing physical conditions and attention-seeking. Participants were not asked whether they believed symptoms were consciously simulated but this emerged nonetheless as an important tenant in their understanding.

A variety of views aligned to psychological models of functional patients emerged. Misinterpretations of normal physiological problems, anxious personality types and environments leading to stress were all examples of possible predisposing factors in the emergence of functional symptomatology.

A number of participants argued that some functional stroke mimic patients have anxious personalities and over-interpret natural physiological changes within their bodies. This is the view that tendencies to be overly-primed to normal somatic processes can lead to misinterpretations and catastrophic construals of minor illnesses:

> *"I think a lot of these patients, whatever is going on in their life, they do maybe have a virus, a bit of an inner ear problem and all of a sudden they sleep funny on their arm or wake up with pins and needles, and it just sort of rolls out of control. They end up coming to hospital because they're dizzy, feel sick, they've got pins and needles in their arm or they are feeling a bit weak and lethargic, and they're already down"* (Nurse consultant, female)

This view is echoed in the psychological literature where there is evidence that misdirected attentional processes and misinterpretations of normal somatic symptoms could be linked to patients' symptom attributions (Brown, 2004).

Some staff members believed that functional patients' presentations were a manifestation of innate, essential processes like personality and that functional patients' tendency to over-interpret natural physiological changes within their bodies was the result of anxious personalities. In these instances it was therefore unlikely for a clinician to posit that these symptoms were within a patient's control and blame was attenuated:

> *"[They are] not just people who have clearly had psychological trauma, but also people who have maybe, their personality has always been to be quite anxious, very introspective about their health or to worry about death, disability"* (Registrar, male)

> *"I feel that those people are getting benefit from being in hospital, getting something out of it…but this girl, I felt that she genuinely, I felt she might have had some underlying psychological issue and this might have been a manifestation of anxiety or a mental health personality. But I just didn't feel that she was doing it deliberately" (Registrar, female)*

The latter participant's unwillingness to attribute blame to a patient with an anxious personality serves to highlight the attribution of blame to functional stroke patients where non-essentialist attributions have been made.

Similar assumptions about the extent of the conscious production or control of symptoms are evident in the view that functional symptoms might be linked to inter-personal conflict. A number of staff members mentioned the possibility that problems within the family might account for symptoms:

> *"They are worried about something and when you dig a little deeper, they are having stress back home or some difficulty"* (Senior house officer, female)

Another clinician believed functional symptoms could be a manifestation of both personality and difficult social situations but patients were not conscious of this:

> *"I honestly think they have a lot of problems, socially and with themselves, that their body was projecting all these issues, but they were not aware of what they were actually doing"* (Senior house officer, female)

The proposals that functional symptoms might be caused by misinterpreting normal physical processes, anxious personality types or patients' social environment mirror some of the current psychological literature on functional symptoms. As previously described, there is good evidence that misdirected attentional processes could be linked to misinterpretations of normal somatic symptoms. Erroneous symptom perceptions can emerge from biases in a person's existing health knowledge (Brown, 2004) while distraction techniques can reduce the experience of symptoms (Barsky et al., 1988). Personality traits may also play a role. Watson and Pennebaker (1989) argue that functional symptoms may be linked to individuals' general predisposition and affectivity. Childhood experiences of parental illness are linked to functional symptom onset (Hotopf, 2003) and there is evidence that traumatic events like childhood physical and sexual abuse are risk factors in the experience of medically unexplained symptoms (Lackner, 2005).

While these clinicians' attributions echo mainstream psychological literature, the symptom causes proffered in interviews tended to be unidimensional in scope. Current theories of

functional symptoms highlight the self-perpetuating and multi-factorial nature of symptom cause (Deary et al., 2007), best illustrated by Engel's (1977) biopsychosocial model where symptoms emerge and are maintained by a multiplicity of environmental, cognitive, behavioural and physiological factors.

A second, different view of functional symptom cause also emerged. Here, symptoms were attributed to conscious feigning for secondary gain – the benefits derived from being unwell. Staff members who expressed this view maintained that patients performed their symptoms. Staff often expressed anger and annoyance at the perceived dishonesty:

> *"It's frustrating. Because why would you actually fake a stroke? A stroke is life changing…disables someone for the rest of their life…so imagine that person has a stroke when you're there, thinking, "Oh well, I've got stroke" when you don't really have. So it is frustrating" (Nurse, female)*

From this perspective, functional patients are explicitly compared to stroke patients. This view also implies that patients can control their symptoms and do so for secondary gains. A number of interviewees gave examples of potential advantages they believed patients sought. Financial remuneration was one:

> *"The people who I think are getting some kind of benefit from the situation, the people who are trying to get you to sign benefit forms, or who are on the personality-disorder type spectrum, I feel quite annoyed with them and I know it's not professional" (Registrar, female)*

Attention-seeking from staff, friends and family members was another causal attribution. Some staff believed these were conscious attempts to gain the sympathy derived from having a physical illness:

> *"Sometimes they, how should I put it, they need attention, from other people. So they are complaining that they cannot move their legs and hands to get attention back from other people" (Senior house officer, male)*

> *"What motivates them? Could be attention, eh, you know, maybe they've got their own personal reasons, you know, I don't know but it could be financial, it could be a whole lot of things" (Nurse manager, male)*

Another staff member believed that while some patients engaged in conscious attempts to feign symptoms most functional patients were motivated by unconscious processes:

> *"In the textbooks, it's called 'gain' but I don't think it means as in, they are consciously, I mean there will be a small proportion who are, almost old fashionably, called 'malingering'. I don't think that's a very big proportion at all. But there are people who, it's probably unconscious who, their whole life is wrapped around their illness…their partner has become their carer, not just financially, they are excused from tasks that they might have to do" (Registrar, male)*

Help-seeking behaviour and primary and secondary gain do feature in psychological models of functional symptoms. Help-seeking behaviour can increase when people misinterpret physical sensations as signs of illness (Kirmayer & Taillerfer, 1997). There is evidence that some patients with somatisation disorder may be more likely to have experienced threatening life events where their symptoms have the potential to illicit some secondary gain (Craig et al., 1994).

Clinicians who believe functional symptoms are feigned however differ from the established literature on functional symptoms in two important ways:

Firstly, to be diagnosed with functional symptoms under DSM-IV (APA, 1994) and ICD-10 criteria (WHO, 1992), deliberate feigning of symptoms has to be ruled out. The interviews suggest that some clinicians have conflated feigning and functional symptoms. If a clinician concludes that a patient's symptoms are intentionally produced, the diagnosis will change to factitious or malingering disorder. However, the evocation of 'unconscious' motivation is a common element in clinicians' understanding of functional disorders since Freud. Stone et al. (2005) note that patients' own awareness of their functional symptom control will fluctuate and while they may begin with little awareness they may gradually gain conscious control or vice versa. Given the complexity of this clinical picture, it is arguably futile for any clinician to accurately detect and delineate deception from unconscious processes. Despite this, clinicians in these interviews appear relatively preoccupied with the issue and it appears to play an integral role in their beliefs about functional patients.

Secondly, when psychological theories do mention secondary gain, they often conceptualise it as a maintaining rather than explanatory factor, something which perpetuates an already existing symptom or arises due to stressful life events (Craig et al., 1994). While secondary gain may be part of a functional presentation, it is unlikely to be a simple connection between seeking advantages and simulating symptoms.

In summary, while some clinicians hold varied, nuanced views on functional symptom cause and suggest personality, stress, traumatic life events and the misattribution of normal bodily processes account for symptoms, a proportion of clinicians hold negative attributions,

suggesting that the need for money or attention from friends and family consciously motivates patients to perform their symptoms.

3.3.2.3 Interactions with patients

Participants were asked what kind of diagnostic labels they use when they diagnose functional stroke patients and how they approach such conversations.

Two styles of interaction emerged; the first was characterised by clinicians who employed obscure terms when discussing functional symptoms with patients while the second group used a more advanced system of explanation reliant on metaphorical language or demonstrative techniques.

The first category included clinicians who said they often use obscure language in order to avoid difficult conversations. When asked which terms they most commonly used, most mentioned the term 'functional' or 'non-organic'.

> *"We often use the word 'functional'*
>
> Do you think [the patient] understands what that means?
>
> *No. That's part of the reason why we use it. When a healthcare professional says the word…it's our way of telling them, without telling them" (Senior house officer, male)*

This clinician purposely avoided addressing the true nature of patients' symptoms. From this perspective, the patient might be satisfied that they received a label with which they could categorise their symptoms but such an approach may cause problems in the longer term when patients seek help post-discharge without a clear understanding of symptom cause.

Using an obscure label can operate as a means by which to avoid difficult conversations that require the use of psychological terminology, something a stroke clinician may feel unprepared for or believe is outside their field of expertise, competence, or responsibility.

Clinicians may also worry when giving a functional diagnosis that they are labelling a person which could lead to stigma once the patient is discharged:

> *"Families tend to come along with the whole, "So what's causing this then?" and it's a difficult one. We don't want to say, "We think this is functional" because there's a lot of stigma associated with that, that it's a psychiatric problem, rather than an organic problem so you just have to phrase it like, "Well, sometimes we can't really explain it". But what we can do is say, "We've looked in every place where it could be causing that*

> *problem and we can't find anything wrong and there's nothing here we can fix, from a medical perspective" (Senior house officer, male)*

'Label avoidance' is a key feature in Corrigan's theory of self-stigma where a person with a mental health problem avoids seeking treatment because they wish to avoid receiving a stigmatising label. In this case, there is a kind of role reversal where the clinician is aware of the negative mental health stereotypes and wishes to avoid labelling the patient (Corrigan & Wassel, 2008). While the impulse might be commendable, avoiding the issue completely may indirectly reinforce stigma as patients can read anything into the resulting diagnostic vacuum. Whether they are given 'functional' or 'conversion disorder' labels, a watered down explanation of their symptoms, or none at all, they are inpatients on an acute ward and will expect the normal medical processes of assessment, diagnosis, and treatment to proceed.

Stroke clinicians may avoid lucid explanations in order to avoid potential stigma but they may also feel restricted in the treatment they can offer. By withholding a diagnosis, clinicians may not feel as obliged to treat or give referrals:

> *"We're doctors. So if someone has a stroke, I know what the risk factors are. I have drugs I can give to that patient to minimise that risk. I feel much more comfortable speaking...once I explain, 'You've had a stroke', they understand. But once you go down the functional route and say to someone, 'There is nothing wrong with your brain. Rather than a problem of the brain, this is a problem of the mind, this is a mental health issue or a psychiatric issue' there is a lot of stigma attached to that" (Registrar, male).*

A possible alternative explanation is that staff might not know what caused a patient's symptoms and are unwilling to give any diagnosis. Obscure language and terminology benefit clinicians who do not want to risk giving a misdiagnosis:

> *"The consultant will speak to the patient…you know they normally use words like, 'We don't think that this is stroke, it could be something else, but we don't think you need to be in hospital and we would refer you to our colleagues'"* (Nurse manager, male)

Giving a negative diagnosis like 'we found nothing wrong', may be reassuring to the clinician – they have addressed the symptoms by conducting diagnostic tests and haven't caused harm by recommending any treatment or tagged the patient with a potentially stigmatising diagnosis. In this sense, a non-diagnosis or a negative diagnosis mitigates risk and uncertainty:

> *"You have to phrase it like, 'Well, sometimes we can't really explain it' but what we can do is say, 'We've looked in every place where it could be causing that problem and we*

> *can't find anything wrong and there's nothing here we can fix, from a medical perspective'…If you sort of say to people, 'Look', they feel like we're accusing them of making things up then it tends to be quite hostile"* (Locum senior house officer, male)

Some clinicians were aware that diagnostic vagueness could be discomforting or even upsetting and noted the importance of a positive explanation. Even clinicians who recognised the value of this, however, still resorted to slightly obscure explanations and appeared to approach their conversations with patients with the expectation of confrontation:

> *"Functional illnesses are almost kind of like a diagnosis of exclusion because it's very hard to do objective tests and say, 'Yes, that's functional' so sometimes you've got a limited information exercise. You can only do a limited number of investigations…you try to reassure the patient and say, 'Look, I don't think it is an organic problem…' but then using that term, 'I think' rather than 'Everything shows' gives them a way in that they sometimes can confront you, 'Well, if it isn't, what could it be?' I try to explain that there are things such as functional problems, inorganic problems or a manifestation of an emotional or stress related problem"* (Registrar, male)

Obscure terms and diagnostic vagueness may serve a further purpose. In referral letters, they can act as signals to other clinicians in the care pathway. Obscure terms can suggest the presence of a functional aetiology without offending patients or running the risk of misdiagnosis.

> *"The letter that the patient takes with them…we try not to write under diagnosis, 'Functional presentation', although, that is probably better than, what's the other one? 'Conversion disorder', you know, so what do you put there? Sometimes I just tell the doctors to write, 'Negative MRI with neurological presentation' or something like that, which I know is woolly and fluffing it up a bit because we don't know what to write and it is a very uncomfortable position to be in because you know there is something wrong with these people"* (Consultant nurse, female)

Similar methods were found to be employed in neurologists' letters to GPs (Kanaan et al., 2009). Letters written in the early stages of the diagnostic process often contain coded messages to GPs that attempt to balance neurologists' duty to be honest and accountable while not offending patients. Codes used included 'elaborated weakness', 'inconsistent' and 'functional symptoms'.

Other terms that emerged from these interviews included migraine and multiple TIAs:

> *"We do do things like say, for example, "This is probably a migraineous phenomenon" which probably covers up likely functional things"* (Neurology registrar, male)

> *"You always want to try and get the best, as good a diagnosis as possible because, you know, mislabelling people can be really destructive and that's as much giving somebody the label, 'TIA' which is attached to them for their life and you know, 'multiple TIAs' is a common diagnostic label and it's just not something, in real life, in actuality, it's not common for people to have recurrent TIAs. But they get labelled with that and they pushed down a certain diagnostic pathway all the time…I think often it is just a catch-all term of 'Well, we don't really know what to call it' or 'We'd rather not broach the subject and call it TIA'"* (Registrar, male)

As this clinician points out, giving a vague or false diagnosis could be actively harmful to patients. TIAs are difficult to diagnose and a clinician might find it easier to give a TIA than a functional diagnosis. TIA patients' quality of life scores are comparable to stroke patients, despite the temporariness of their symptoms (Franzen-Dahlin & Laska, 2012). Post-diagnosis, many TIA patients live in fear that an episode will reoccur and limit their everyday activities (Spurgeon et al., 2013) so it is a diagnosis that should not be given lightly.

There may be something especially damaging about such a practice in an acute inpatient setting, where the patient may assume that due to the specialisation of skills there, a diagnosis given there might hold more weight than a diagnosis from elsewhere. They may be more likely to change behaviour or be emotionally affected by diagnostic information from these clinicians. In such a setting, diagnostic vagueness from acute care staff might be particularly worrying.

The final part of this section discusses the more direct means of communication utilised as well as the use of metaphor and non-verbal techniques employed by stroke staff.

Some staff described being direct in their approach to functional diagnoses:

> *"Sometimes I think the truth is just better than not hearing it. So, if you have these functional patients coming in, you'll always have them coming back in because if you don't tell them, 'Actually, this is functional' then they will present with the same symptoms again, thinking, 'I definitely am having a stroke'"* (TIA nurse, female)

Other participants described utilising more complex explanations when talking to patients, relying on metaphors and similes to help patients better understand their symptoms. This was most commonly expressed as conceptualising the body as 'a computer' where wiring could go awry:

> *"Spend time with them, sit down with them and talk about wires in the brain, that it's a bit like a computer and the wires get crossed and things won't work.…I don't know how I put it but I put it in such a way as, 'We believe you believe'"* (Nurse consultant, female)

The 'mind as machine' metaphor is not new in cognitive psychology (Pinker, 1999) or philosophy (Dennett, 1984; McCulloch & Pitts, 1943; Rumelhart, 1989) but more recently it has been proposed as a way of explaining functional symptoms without inferring blame or guilt. A Dutch survey of 343 neurologists found 38.8% used a computer metaphor telling patients their 'hardware' (or brain tissue) was intact but they were experiencing a 'software' problem (de Schipper et al., 2014). GPs treating unexplained medical symptoms have reported relying on mechanistic metaphors like 'load and capacity' concepts (olde Hartman, 2009).

While such explanations help facilitate discussion about psychological or psychosocial problems, it has also been suggested that reliance on metaphor can ignore the finer details of diagnosis (Mabeck & Olesen, 1997). The mechanistic metaphors may not be helpful to everyone and most patients will likely understand explanations within their own pre-established cognitive schemas. By taking time to first understand patients' own conceptualisations, clinicians might be able to offer explanations that best suit the patient.

Some clinicians described how the content of their explanations was less important than the way in which information was communicated. Examples include highlighting neurological inconsistencies for the patient, a technique recommended for neurologists in their assessment of functional symptoms (Stone et al., 2005):

> *"I try using formal tests like the Hoover test…I normally do talk to them. I do it in a non-confrontational way. I say 'The weakness, you maybe feel that the weakness is there, but when I was trying to distract you, when I pulled my hand away, the weakness is not as bad as you make it out to be but I don't know if maybe you're perceiving that it's weak or it is actually that weak'"* (Neurology registrar, male)

Similarly, clinicians believed that the language used in the clinical consultation was less important than the confidence with which the clinician spoke:

> *"I think a lot of the time it depends on your confidence as a clinician. If you make a confident diagnosis and they trust you, to me, that is the absolute core element…If they don't trust you, it doesn't matter what you say it is" (*Neurology registrar, male).

While the content and language a clinician chooses is important, their non-verbal communication is also relevant. There is observational evidence that interactions between

doctors and patients on stroke wards may be impaired compared to interactions on general medical wards. They may be more likely to be ignored, less likely to be given eye contact and less likely to be given help if needed (Pound et al., 1999). Non-verbal communication like head nodding, uncrossed arms and legs (Beck et al., 2002), tone of voice and eye contact (Marcinowicz et al., 2010) have been highlighted by patients as important. This is an area that has been explored extensively in general practice with less known on its effects in relation to functional patients.

In summary, there is evidence that less experienced clinicians resort to obscure language in a bid to avoid confrontation or labelling patients. In other cases it may be to convenience the clinician themselves and help avoid taking responsibility for the patient. More experienced clinicians, have developed nuanced modes of communication and use metaphor and positive non-verbal techniques to communicate with patients.

3.3.2.4 Responsibility and risk

The theme of risk and the accompanying responsibility was a subtext in the previous two sections. Some clinicians believed that patients were consciously producing symptoms and were personally responsible for their admission. Others described feeling responsible for how they interacted with patients and were worried they might imply blame, guilt or infer stigma if they used psychiatric labels. However, some staff members believed that they were not as clinically responsible for functional patients as they were for stroke patients.

This section examines how different clinicians prioritise patients and how they manage risk and uncertainty through diagnosis, treatment and referral patterns employed. Stroke clinicians continually deal with risk but it appears that once the risk of stroke has been mitigated, there is a deferral of clinical responsibility.

There was a tendency for clinicians to view functional stroke patients as both outside their clinical remit and not a priority. This was likely due to the acute and specialised nature of the HASU and the clinical severity of stroke itself.

> *"In a stroke unit, you've got to, you have such a high turnover and such a high volume of patients coming in who are really, really very sick patients, very unwell, and people, as soon as you say, "Okay, we can't find an organic lesion for their problems", everyone kind of loses interest a little bit and just like, 'Yeah, it's not for us, it's not a neurological thing, there's nothing we can do about it'"* (Locum senior house officer, male)

One doctor described feeling more at ease taking responsibility for stroke mimic patients with physical causes. This may be because doctors feel more competent treating physical symptoms but there was also a view that physical comorbidities were more important:

> *"You know, I recognise what I can do and what I can't do and psychiatry is something I'm not particularly interested in, I've not particularly got much skill so it's a job for someone else…common stroke mimics, organic stroke mimics, things like Bell's Palsy for example, we'll often manage those ourselves"* (Locum senior house officer, male)

An unsympathetic view of this account is that the lack of priority is fuelled by a wish not to interact with people perceived as having mental health problems (Segal et al., 1980). The General Social Survey found half of adults surveyed in the US were unwilling to spend an evening socialising with or working next to a person with a mental illness (Martin, 2000).

Such avoidance may directly affect the patient. Kirmayer and Taillerefer (1997) argue that negative doctor-patient interactions can increase the distress associated with symptoms and reinforce emotional arousal, illness worry and disability. Staff members however tended not to see themselves as part of patients' interpersonal network and certainly not as potential contributors to or re-enforcers of distress.

This attitude may result from a lack of interest in functional stroke patients generally, but it also reflects the specialisation of care on a HASU ward. Clinicians view the ward as a highly effective centre for stroke treatment and, from this perspective, functional stroke patients are usurpers of beds, time and resources.

This view is likely tempered by the clinician's role on the ward. Clinicians in managerial positions, responsible for tracking the ward's performance through reporting systems like the Sentinel Stroke National Audit Programme (SSNAP) may be more likely to see functional stroke patients as disruptive to the HASU and may be more acutely aware of the demand for beds and the costs involved in treating patients:

> *"And I would never stand up there and say a patient doesn't deserve a bed, but I'm really sorry but my acute stroke patient in A&E does deserve the HASU bed more than the mimic patients in there and you have to be realistic, and people can shoot me down, but obviously that patient can be managed elsewhere, whereas a HASU patient needs to come to HASU otherwise their outcomes are going to be terrible"* (Nurse consultant, female)

There is a high demand for HASU beds and a finite supply and this will inevitable place pressure on clinicians. The system is designed to measure stroke patients' clinical outcomes.

Their outcomes reflect HASU clinicians' performance and the good management of a ward through the mandatory reporting in UK-wide stroke monitoring systems. SSNAP does not audit the outcome of functional stroke patients so the management adage 'you can't manage what you don't measure' may apply here.

However, the monitoring of outcome may not always work against functional stroke patients. Physiotherapists abide by SNNAP guidelines and prioritise patients according to their time of arrival on the ward rather than their diagnosis:

> *"We have to go by the SSNAP data. All the new patients have to be seen within 72 hours. So over a weekend, we actually see those that come first…It's a bit of a lottery, as in who has had scans, who has been washed, who is actually free"* (Senior neuro-physiotherapist, male)

Functional patients will also be thoroughly examined. Under SNNAP standards, 90% of eligible patients must receive thrombolysis and 100% of patients must be scanned within 12 hours of symptom onset (London Strategic Clinical Networks, 2014). Because of the potential uncertainty and inconsistency in functional patients' symptoms, their diagnostic assessments are often exhaustive. While a patient with haemorrhagic stroke might receive only a CT scan, a functional patient will often get both a CT and an MRI scan:

> *"Sometimes we repeat the scan, just to make sure that we're not missing anything"* (Senior house officer, female)

> *"The medical team, regardless of how unstroke-like the presentation might be, you know, 'Drank six bottles of vodka', 'Patient had some cocaine', 'Heroin addict', they all come back for an MRI…it's the same treatment for everybody…the consultant…they're still adamantly serious that every functional patient has an MRI. They cannot risk sending them home from the emergency department"* (Consultant nurse, female)

Being thorough may help reassure the patient but it also serves the purpose of protecting the hospital from any potential litigation.

There were differences in the role personal intuition played in identifying functional patients and this tended to vary depending on the clinician's experience. Some clinicians describe having an intuitive awareness of what non-stroke looks like:

> *"When you're a stroke nurse, or you work in stroke for a while, you automatically start knowing the brain, you start knowing what can be affected and if these people are*

> *presenting with symptoms that doesn't match up with what they're telling you, you start thinking, 'You know what, this isn't it'"* (Nurse, male)

Another clinician described identifying potential functional stroke by noticing idiosyncrasies in their presentations:

> *"There is a lot of anecdotal evidence that things like dark glasses…for epileptic patients, if they came in with a teddy bear to telemetry then the likelihood of them being non-epileptic was statistically significantly high… you are probably subconsciously analysing lots of subtle aspects and cues, but you do get, I get an overarching sense of, 'This doesn't look like...it's going to be a stroke'"* (Neurology registrar, male)

Some doctors argued that having less clinical expertise meant your personal threshold in accepting risk was lower and you were more thorough in your assessment.

> *"The newer [doctors] are the ones that examine them more accurately, more in depth"* (Senior house officer, female)

Stroke is relatively easy to diagnose compared to other neurological disorders like Parkinson's disease or multiple sclerosis. There may be a tendency to conflate diagnostic techniques like ordering assessments such as MRI and CT scans with good care and the administration of effective treatment. Clinicians were happy to discuss in detail how they ruled out physical diagnoses but gave little detail on the kind of treatment they would recommend or the referrals they make:

> *"Most of the time they're there, it's just pat them on the back and off they go, that type of thing and I really don't know what happens"* (Consultant nurse, female)

One clinician argued that not offering treatment was in itself useful and patients become more self-sufficient as a result:

> *"Often it's better to actually give them advice, discharge them without onward referral and sort of teach, show them how they can access services if they require it, advising them that they will improve spontaneously, that usually seems to work"* (Neuro-physiotherapist, male)

Some clinicians described employing more positive strategies:

> *"If you're reassuring them that you have taken their ailment seriously and that you're helping them to try and get better, then that is the most important thing. So I think*

> *that, just by saying, 'This is a functional hemiparesis. This is how we're going to approach it, this is what we know about it', things can get better"* (Neurology registrar, male)

Even if a clinician felt responsible for the care of the patient, many did not feel supported by the stroke system in making appropriate referrals. Many clinicians felt adrift when it came to knowing how to treat or where to refer functional patients:

> *"It depends on the patient, if they ask to be referred. To my knowledge there's no sort of protocol or pathway of whether you get referred for psychiatric or psychological treatment based on their functional symptoms"* (Locum senior house officer, male)

> *"There doesn't exist a clear pathway for patients who haven't had a stroke. If we say this is a functional stroke mimic…there's not a defined pathway on how we would go about managing that. It would literally just be a case of discharging them"* (Senior house officer, male)

One registrar believed referrals were difficult to make generally as they were reliant on who the referring clinician knew. Coupled with this, she believed mental health services were not well integrated within physical health care:

> *"A lot of the time, making referrals in the NHS involves knowing who to email, who to call…because you have to know the services available. I've worked in this hospital for basically four years and I know a lot about the services here but I'm not sure about the mental health side of things and where that fits in"* (Registrar, female)

Some clinicians proposed concrete treatments for patients. Follow-up appointments in the setting in which patients were first admitted were recommended by one clinician arguing that continuity is important:

> *"If they came in with a movement disorder that we thought was functional, then I would say that they should be seen in a movement disorder clinic for the first follow-up…they may well go away and come back and they may have some questions that they need to go over things again, just to feel secure that you didn't miss the diagnosis"* (Neurology registrar, male)

Continuity of care is valued by patients with medically unexplained symptoms (Hartz, 2000) but it has traditionally been seen as a responsibility for GPs rather than secondary services.

Psychological support was another proposal:

> *"I really think that they need support groups and therapy, behavioural therapy, and unfortunately we just let them go and hope the GP will do that for them"* (Senior house officer, female)

There was a general tendency to describe or outline services that could be provided by other teams or departments rather than specific interventions that the stroke team or stroke clinicians themselves could provide. There appeared to be little desire to improve their own training or increase access to educational opportunities or a will to reorganise their own team.

In summary, clinicians place a high degree of importance on the mitigation of risk associated with physical disease and it appears that once the lack of physical disease is firmly established, clinical responsibility is extenuated and the clinician's priority becomes the discharge and referral of the patient.

3.3.2.5 Systemic issues

A number of clinicians described the institutional pressures of working within the NHS as a clear impediment in their day-to-day jobs. The high volume of admissions and the limited number of staff available was one such problem:

> *"There is pressure to see the patients. They should all be seen every day and they should all get 45 minutes every day…there is one physio for 13 HASU beds. The maths doesn't add up"* (Physiotherapist, male)

This was highlighted by another participant:

> *"Our staff is not very big for the amount of patients that we get within a week. It's not that they are inappropriately discharged, but they are discharged without all of their needs covered"* (Senior house office, female)

This was described elsewhere as a kind of supply/demand problem. The demand for beds was high with a limited supply:

> *"We've got 12 beds, two are taken by tracheostomies and we have 250 admissions every month, now that's 250 out. There's not time. Average length of stay is 2.5 days for 40% of patients so turnover is massive"* (Nurse consultant, female)

> *"It is also the nature of doctors, the way you have a happy life as a doctor is if you can send patients home, you send them home because every single patient, even if there's nothing wrong with them, it's another person you have to see each morning…it all adds*

> *to your workload, so if someone is fit for discharge, you need to discharge them".* (Locum senior house office, male)

The hierarchal nature of the acute stroke ward might aid its smooth running but it might also impede some staff members from being creative in their clinical response to functional stroke patients. One participant felt that nurses were constrained by doctors in how much information they could give to functional patients.

> *"It's not that nurses can't do it, but if you're being seen by a consultant on the ward round and the consultant isn't really saying that you are functional but having a senior nurse or junior nurse going in and saying, 'You're functional'…I feel that it should be initiated by the consultant. Seeing that you're the consultant, it's your speciality"* (TIA nurse, female)

In summary, clinicians face impediments in the proper care and treatment of functional patients due to the high demand for beds and pressure to discharge patients promptly. Less senior members of staff also feel powerless in relation to the diagnosis of patients and the choice of treatment and referral pathways.

3.4 Discussion

3.4.1 Main findings

The survey study suggests stroke clinicians believe their role is to provide reassurance and support to functional patients and that they view the primary care setting as the most appropriate for the treatment of patients. These findings correspond to results from surveys of GP attitudes who also saw their main role as providing reassurance and support to functional patients (Reid et al., 2001b; Sirri et al., 2017). GPs themselves endorse primary care as the most appropriate setting in which to treat patients.

Like Reid et al.'s study, our survey results found stroke clinicians believe functional stroke patients are difficult to manage and don't believe that they have an undiagnosed physical illness. Stroke staff felt functional stroke symptoms have been neglected by research and there should be more guidelines available to staff. Unlike Reid's survey, stroke clinicians don't believe functional symptoms can be explained by personality disorders and fewer agree that these patients have a psychiatric illness (43.4% of stroke clinicians versus 63.5% of GPs). It is possible that stroke clinicians were unaware or unsure what personality disorders were and as a result avoided endorsing the statement. Compared to GPs, stroke staff spend less time with

individual patients so they may be less likely to suspect an underlying psychological or psychiatric aetiology.

The qualitative interviews reveal more varied and nuanced attitudes towards patients.

Firstly, when asked about the possible cause of functional stroke symptoms, clinicians make multiple symptom attributions like the seeking of financial gain, requiring attention from family and friends and the misinterpretation of normal physical problems. In contrast to the survey findings, the qualitative results indicate that some clinicians believe personality does play a role in the emergence of functional symptoms.

In making these attributions, clinicians revealed the extent of volition they believed patients had over their symptom production and how much blame they apportioned to individual patients for their admission. Clinicians who made internal or essentialist causal attributions like personality seemed less likely to ascribe blame to the individual patient. Where clinicians believed symptoms were consciously produced, there was a sense that patients were culpable for their admission.

This, in part, echoes existing literature highlighting the often entrenched negative attitudes of doctors towards patients with unexplained or functional symptoms where patients are characterised as self-focused, irritable, difficult and demanding (Engel, 1959; Friedman et al., 1963). The current work suggests a shift in attitudes wherein a degree of responsibility or motivation is ascribed to patients, but this does not inevitably lead to rejection and blame. This is compatible with our survey results where clinicians stated they felt their primary role was to provide reassurance and support, followed by counselling and appropriate psychological management for these patients. More education on the current causal models of functional disorder might help reduce misconceptions and potential stigmatising behaviour.

Two styles of clinician/patient interaction emerged. The first type saw the clinician attempt to address the functional diagnosis but avoid direct conversations through the adoption of vague terms. Doctors feared misdiagnosing patients and also stated they did not want to use a potentially stigmatising label. There may be a certain level of psychological projection here whereby the clinician themselves has endorsed negative stereotypes of functional patients and is concerned patients will respond badly to the label. Using vague language helps protect the clinician from difficult bedside conversations but may leave the patient confused and in a diagnostic limbo.

A second style of interaction saw clinicians employ a range of techniques to try to convey the meaning of the functional diagnosis. These clinicians employed metaphors and demonstrative

techniques to try to give positive diagnoses. This is a positive finding as there have been attempts in recent years for clinicians to use positive assessments and diagnoses when treating functional patients (Stone et al., 2005). Clinicians are advised to try to reduce patients' anxiety, make positive functional diagnoses, to explain the diagnosis as much as possible, and if the clinician feels there is a co-occurrence of physical and psychological symptoms, to discuss this (Reuber, 2005). How to adapt these steps to the specific needs of the HASU would be helpful for future research.

Risk and responsibility was a prominent theme throughout our interviews. Coping with risk is an integral part of a stroke clinicians' job where the consequences of giving a false negative stroke diagnosis could be severe. Clinicians felt responsible for functional stroke patients up to the point they could definitively rule out stroke. The diminution in clinicians' sense of responsibility for functional patients is fortified by systemic issues like the lack of available beds and staff shortages, but this may be somewhat of a pretext when shirking responsibility. Once the risk of stroke is mitigated, the sense of responsibility for the patient fades. While clinicians were happy to discuss the diagnostic tests they used and the ways in which they imparted diagnostic information they were often vague when it came to discussing their treatment and referral approaches. Many mentioned the lack of guidelines and referral options for these patients, corresponding with the survey results where respondents all agreed that there was a lack of available guidance on how to refer functional stroke patients.

Functional disorder patients in neurology outpatient settings report impairment similar to patients with physical symptoms and experience more distress than neurology patients (Carson et al., 2011). In acute settings like the HASU, it is likely that distress is even higher. The diagnosis of functional disorders deserves the same degree of effort and care as a physical disorder and when the diagnosis is reached, clinical responsibility should not be abdicated.

HASU guidelines direct staff to discharge stroke mimics within 24-hours of their admission. While this might be straightforward for medical mimic patients, functional disorder patients may be left in treatment limbo. While an educational programme for stroke staff might help improve clinicians' understanding of and ability to convey a functional diagnosis, guidelines are needed to improve the systemic care and referral of functional patients across HASU sites. Such calls have been made elsewhere and have increased in recent years (Caruso & Manganotti, 2016; Segal et al., 2012).

Finally, it is worth considering these findings within the context in which clinicians work and the extent of their specialisation in stroke medicine. Their views are influenced by the severity

of the stroke cases they see. In this light, staff often see functional patients as healthy and extremely lucky.

Clinicians don't live in a social vacuum and the wider cultural importance bestowed on 'being healthy' is worth mentioning. Some sociologists have described the ideological pursuit of good health in high income countries as morally and ideologically driven. In capitalist economies, self-control and responsibility for one's own health are increasingly valued (Crawford, 2006). To some clinicians, functional patients violate these social norms and may be seen to directly contravene and undermine these moral virtues.

3.4.2 Strengths and limitations

Our survey study is the first to assess stroke clinicians' views on and experiences with functional stroke patients. The questionnaire sampled a wide geographical area within the UK, including rural and urban regions and surveyed a range of disciplines and grades. While our semi-structured interviews were based in one HASU and may therefore have limited representativeness, our survey study addresses this concern.

The survey has a number of limitations. Firstly, there were not enough survey respondents to allow for robust statistical comparisons between urban and rural sites or staff members' years of experience. Secondly, a more extensive questionnaire might help tease apart engrained attitudes towards functional stroke patients. Attitudinal questionnaires assessing mental health literacy like the 'Mental Health Literacy Questionnaire' (Jorm et al., 2006) or social stigma scales (Modgill et al., 2014) would have been interesting additions. It was important however that the questionnaire was completed quickly as staff were asked to complete questionnaires during work hours. The number of response scales we could include was therefore necessarily restricted.

The method we employed to distribute the questionnaire could limit the extent of interpretation in three ways. Firstly, a clinician within the stroke team was asked to distribute surveys and given a number of weeks to complete the task. Given staff members' busy schedules, this request often had to be repeated. Despite this, the response rate at some sites was low. Some stroke sites are therefore under-represented in our survey. It is possible that the sites with higher response rates have well-established procedures and clinical insight into how to treat functional stroke patients, potentially biasing our results. However, given that twelve sites were included, this bias should be attenuated somewhat.

Secondly, asking a senior clinician within the team to distribute questionnaires meant it was difficult to assess the non-response rate or to investigate whether those not responding were systematically different to those that did.

Thirdly, as the staff member in each team who agreed to distribute surveys often held a senior position, it is possible that their influence affected some responses. Though surveys were confidential, it is possible staff members were worried that their views might be noted by the person collecting their questionnaires and they may have given more socially-desirable answers as a result.

The qualitative interviews allowed for a more in-depth analysis of the issues and allowed for the elicitation of a richer breadth of information. The interviews took place at one urban site so representativeness may be limited. The response rate to the qualitative study was high and recruitment of different disciplines was representative of the staff working at this ward. The interviewer was embedded on the ward which allowed her to gain greater insight into its culture and the procedures employed there.

Spending a substantial block of time on the ward was helpful for the researcher but it may have had a disadvantage. Clinicians knew the researcher was researching functional presentations on the ward. It is possible that there was an observer effect whereby staff became primed to the topic of functional symptoms as a result of knowing research was being conducted on the issue and may have changed or adapted their clinical behaviour as a result of the presence of the researcher.

There may also have been a kind of ‘contamination’ within the stroke team. Clinicians who were interviewed may have discussed the topic of functional symptoms or the content of the interviews with other clinicians on the ward who were then subsequently interviewed. This might have influenced their view of the subject. Social desirability bias can also not be ruled out. All interviewees were assured that the interviews were private and confidential and were encouraged to speak freely without fear of judgement.

It is also possible that the researcher, in the use of interviewing techniques and thematic analysis, exhibited a form of observer bias in the style of questioning or became primed to notice certain themes more acutely than others. We tried to reduce this by using the same semi-structured interview schedule for all participants, avoiding leading questions and in the presentation of results, giving counter-examples.

The setting of the interviews may have affected the kind of results gained. Interviews did not take place in a neutral setting but rather on the stroke ward and during clinicians’ work hours.

A more neutral setting, for example within the university, might have helped mitigate any such bias although within the bounds of the time available, this would not have been a practical solution. Doctors kept their emergency pagers on them during interviews. In one case, an interview came to an end because of an emergency call. In another case, an interview was postponed for another day. The presence of the pager might have influenced some responses as the researcher and participants were aware that it could go off at any time. Conducting the interviews on the ward however was an advantage however as it gave the interviewer insight into the ward's procedures and protocols.

In the period that the interviews took place, there were a number of junior doctor and hospital porter strikes. It is possible that some of the systemic issues raised as concerns in the qualitative interviews were heightened due to these industrial disputes at the time. However, given that these interviews happened over the relatively long course of ten months, the interviews are less likely to be biased by any single source of industrial or occupational dispute.

3.4.3 Conclusions

Clinicians display some conflicted views on functional stroke patients. They are concerned with the potential misdiagnosis of these patients and show concern about mislabelling or stigmatising patients. Clinicians have varying views on the potential cause of these symptoms but most feel their primary role is the diagnosis and treatment of stroke and the immediate discharge of functional stroke patients. Few have any fixed view on the best referral or treatment option for functional patients but both quantitative and qualitative studies showed stroke clinicians want more information on treatment guidelines and referral options. There is a paucity of treatment and referral guidelines for functional stroke mimic patients and our survey found stroke evidence that staff would like more guidance in this area.

Chapter Four: Qualitative interviews with patients with unexplained stroke symptoms in a hyper acute stroke setting with two-month follow-up interviews.

4.1 Introduction

The previous chapter explored the experiences and attitudes of stroke clinicians in diagnosing and treating functional stroke patients. This study explores the experiences of functional stroke patients after their admission to a HASU and again two months after their discharge.

There is evidence to suggest that those who experience physical symptoms for which there is no obvious biological cause or where there is ambiguity or uncertainty around their diagnosis can endure physiological and psychological consequences. Patients can experience high levels of depression (Henningsen et al., 2003), disability, and distress (Carson et al., 2011). Diagnostic uncertainty has been linked to heightened sensitivity to pain and a reduced quality of life (Wright et al., 2009).

Understanding how a person represents and understands their functional symptoms and experiences during an acute stroke admission is not just a pedagogical exercise. It may help predict their future behaviour and their recovery trajectory. Patients who attribute unexplained symptoms to physical causes are more likely to make frequent visits to doctors while those who make psychological attributions are more likely to experience comorbid depression and anxiety (MacLeod et al., 1998; Rief et al., 2004). Understanding the experiences of functional stroke patients on the stroke ward and after discharge is the first step in the development of theoretical and treatment models.

Previous qualitative research investigating the experience of patients with unexplained symptoms has focused on general practitioner (Ring et al., 2005) or neurology settings (Nettleton et al., 2005). There is considerable evidence on patients' perspectives living with CFS (Broughton et al., 2017; Parslow et al., 2017), chronic pain (Osborn & Smith, 1998; Werner & Malterud, 2003), and irritable bowel syndrome (IBS) (Farndale & Roberts, 2010; Jakobsson Ung et al., 2013) but currently no literature on the experiences of patients with unexplained or functional neurological symptoms admitted to stroke settings.

This introduction provides an overview of the existing literature on patients' own accounts of unexplained syndromes, outlining evidence on the illness narratives patients employ to describe and understand their symptoms, the attributions and illness perceptions they make and attitudes held towards clinicians.

4.1.1 Previous qualitative findings

4.1.1.1 Illness narratives

Through the course of getting ill, being ill and recovering or getting worse, patients adopt ways of understanding and describing the experience, known as illness narratives. Narrative is employed by patients and clinicians and it can be helpful when trying to understand the meaning people ascribe to experience. Taking histories and writing formulations are an important part of a physician's role. The clinical consultation could be seen as a collaborative attempt to construct a narrative and in itself can be therapeutic. Psychotherapy, for instance, is a formal collaboration between therapist and patient where both attempt to construct a narrative through which to understand past experiences.

Traditional illness narratives often take the form of symptom onset experiences, seeking a diagnosis, receiving treatments and eventual recovery. For patients with unexplained or functional symptoms, such narratives may be harder to construct and patients can be left in 'semantic no man's land' (Kirmayer et al., 2004) or 'diagnostic limbo' (Corbin & Strauss, 1985). Chapter Three highlighted the tendency for stroke clinicians to avoid using formal diagnoses and the lack of treatment referrals for patients with unexplained or functional symptoms. In the absence of the normal medical treatment course and, given the often contested nature of functional diagnoses, it is important to understand the ways in which these patients understand their experience.

Frank (1995) proposed three common types of illness narratives, 'restitution', 'chaos' and 'quest'. He argues that patients with unexplained symptoms commonly adopt 'chaos narratives' where patients describe symptoms which have no clear beginning, where disability is conceptualised as something that gets progressively worse, pain is unremitting and physicians are viewed as incompetent. Other qualitative research has highlighted the fragmented or chaotic accounts of unexplained symptoms by patients (Peters et al., 2008).

That patients' narratives can be chaotic is understandable given the frequent lack of guidance offered by doctors within consultations (olde Hartman et al., 2013). Chaotic or fragmentary accounts may arise as patients become aware of the time-limitations on their medical consultations and patients can feel frustration when GPs don't or can't appreciate the extent of their problems (Peters et al., 2008). Patients have often seen multiple clinicians and had many tests, and as a result may find it hard to recall specific elements of their medical histories. Patients with NES often struggle to retain information from doctors and many felt confused after a clinical encounter (Wyatt et al., 2014). In some cases patients see their GPs as

unable or unwilling to help reattribute their symptom experiences or guide their understanding (Peters et al., 2008).

The lack of a clear narrative or structure with which to think about symptoms may have negative consequences for patients. A study of patients with chronic back pain found patients were relieved when they secured an identifiable organic cause and those with no diagnosis felt shame and guilt (Rhodes et al., 1999). While clinicians may view diagnostic uncertainty as an opportunity, for patients, this uncertainty can be disturbing and distressing (Kang, 2005).

4.1.1.2 Illness attributions and perceptions

Closely linked to illness narratives are the causal attributions made by patients. Attributions are the beliefs held by patients about the origins of their symptoms. There is evidence from medicine on how conflicting beliefs on the origins of symptoms between doctors and patients can negatively affect patients' health care (Kaba & Sooriakumaran, 2007; The Lancet, 2013) through competing therapies, inducement of fear in the healthcare system and distrust in the discipline of medicine generally (Diette & Rand, 2007). Physicians operate within the biomedical model but patients may be influenced by their own behavioural and social beliefs (Platt & Keating, 2007). In unexplained or functional cases, patients may be convinced there is a medical explanation while doctors proffer psychosocial explanations.

Robbins and Kirmayer (1991) identified three symptom attribution types. The first are normalising attributions where a person looks for an external or environmental account of their bodily sensations. If they find no external evidence for the symptom they may turn to the second attribution type; physical or biomedical explanations; and thirdly, they might adopt a psychological explanation where the symptom is attributed to psychological states like worry or anxiety.

Other attribution theories do not depart greatly from Robbins and Kirmayer's account. Young (1976) classified lay understandings of illness as either internalising or externalising while Helman (2000) described four attribution types: beliefs about cause located within the individual, the natural world, the social world, or the supernatural world.

Patients with functional or medically unexplained symptoms may make multiple symptom attributions. Rief et al. (2004) reported that primary care patients with unexplained symptoms most frequently believe their symptoms were a result of 'vulnerability to infection or environmental factors'. These patients were more likely to make organic illness attributions compared to patients with other physical disorders. A study of patients with chronic disorders with a 'definite psychosomatic component' found patients held multi-causal explanations

mentioning physical, psychological and social causes like personality, genetics, organs behaving 'beyond their control', poor relationships, and stress (Helman, 1985).

Illness beliefs can affect illness behaviour and health outcomes. Belief in somatic causes can result in more requests for investigations and medications, increased disability at work and the avoidance of physical activity and more visits to GPs (Barsky et al., 1993; Ford, 1992; Sensky et al., 1996). Compared to patients who adopt psychological or social explanations, people who believe a physical cause accounts for their symptoms were less likely to experience stress (Bridges et al., 2009), more likely to have had childhood experiences of illness, and have had parents with a history of physical illness (Craig et al., 1994). Belief may also affect the chronicity of symptoms. Sharpe et al. (2010) reported that patients with unexplained symptoms in neurology who were unwilling to attribute their symptoms to psychological causes had poorer outcomes. For patients with chest pain, the persistence of pain was predicted by their earlier belief that they were prone to serious heart disease (Wielgosz & Earp, 1986).

Different types of functional disorders may give rise to different illness beliefs. Ludwig et al. (2015) found patients with functional limb weakness were more likely to reject psychological causes than NES patients and less likely to consider their treatment effective. A study by Stone et al. (2004) found patients with functional weakness were more likely to find their symptoms mysterious compared to patients with organic weakness.

There is an inherent dualism in these theories regarding patients' illness beliefs. The conceptualisation of lay belief as wholly internal or external, psychological or physical may be overly simplistic and fails to account for the multiple and potentially contradictory causal attributions patients can hold and that beliefs may change over time.

Leventhal et al. (1980) outlined a more pragmatic framework for understanding beliefs, based on illness perceptions. They noted how illness beliefs differ depending on the symptom label a person adopts, whether they believe their symptoms are acute or chronic, their perception of the consequences of their illness on everyday life and their views on curability and controllability. They propose that people are active problem solvers and try to avoid or treat illness depending on how much they perceive the illness to be a threat. There is consistent, though somewhat tautological evidence that frequent health care users believe that their symptoms have serious consequences, that they will continue indefinitely and report high rates of illness worry (Frostholm et al., 2007; Petrie et al., 2007). A systematic review showed an association between illness perceptions and survival in patients with end-stage renal disease (Parfeni et al., 2013) and patients with diabetes and foot ulceration (Vedhara et al.,

2016). A systematic review concluded that there is a moderate to strong relationship between illness cognitions, coping and illness outcomes (Hagger & Orbell, 2003).

Just as illness narratives can be complex, ambiguous and amorphous, illness attributions are likely to be multiple, and even contradictory. The kind of illness beliefs a patient holds and the strength of that belief will be influenced by many factors including the type of referrals they receive, the length of time they have experienced the symptoms, resistance to their beliefs from family and friends, how their symptoms progress over time and the kind of interactions patients have with the medical profession. The latter issue is explored in the next section.

4.1.1.3 Attitudes to clinicians

The previous chapter examined the attitudes and views clinicians hold towards functional stroke patients. This section explores existing evidence on the attitudes patients hold towards clinicians.

Functional disorder patients can view consultations with trepidation. Qualitative studies of functional patients' experiences found patients often fear the judgement of their clinician and worry that their doctor will view their symptoms as 'all in their mind' or worry that they will be seen as fraudulent or time-wasting (Nettleton et al., 2005; Peters et al., 2008). Back pain sufferers also expressed fear that the reality of their pain would be denied and their motives questioned (Glenton, 2003). In these instances, a physical diagnosis is akin to 'absolution' or a legitimation of symptoms. With the conferral of a physical diagnosis, patients can feel exempt from accusations of malingering, hypochondria and mental illness.

Patients may hold differing attitudes to clinicians depending on the doctor's speciality or experience. A study of NES patients found the type of health professional with whom they had had their single worst healthcare interaction were neurologists who did not specialise in seizures. They also reported these clinicians were lacking in knowledge and awareness, that they did not take the patient seriously and their personal perspectives were marginalised (Robson & Lian, 2017). Disagreement regarding symptom cause often lies at the heart of these interactions were a lack of trust and defiance can pervade interactions (Karterud et al., 2010).

A study of patients with persistent somatising symptoms in Liverpool categorised patients' responses to doctors' explanations into three categories; clinicians who patients believed denied the reality of their symptoms; clinicians who sanctioned their own symptom beliefs and a third, less common type were doctors who offered explanations that attributed symptoms in a way which removed any sense of blame. Most commonly however, patients reported

perceiving doctors' views to be in opposition to their own, suggesting the views of the doctor and patient not only differ but can be in active conflict (Salmon et al., 1999).

Such conflict is reinforced when patients believe a doctor is incompetent and the information they hold is limited or wrong (Toombs, 1993). The perception of the fallible doctor can stem from a view that doctors are over-reliant on medical and technical investigations, and that they deny the reality of patients' symptoms (Peters et al., 1998). Unsurprisingly, in cases where patients believe doctor's knowledge to be fallible, patients display a greater readiness to reject their advice (Hunt et al., 1989).

Positive engagement with patients emerges as an important part of the patient-doctor interaction. A study of primary care patients with somatoform symptoms found between 40 - 50% of patients felt their physicians showed only moderate concern for their symptoms. Patients who perceived their physicians as caring about their unexplained symptoms were more likely to rate physicians as having shown respect for what they said, spending a suitable amount of time with them and receiving the best possible health care (Hartz, 2000).

These findings suggest that the non-specific effects of the medical consultation are important. Improving communication skills, collaboration techniques, conflict management skills and addressing patients' health beliefs directly might improve these doctor-patient interactions. The warmth of the relationship, the experience of being listened to and taken seriously and the sense that a doctor takes responsibility for the patient's care are important for recovery.

4.1.2 Aim of research

Much of the existing research on experiences of functional patients comes from primary care and neurology outpatient settings but there are fewer accounts regarding the experiences of patients in acute inpatient settings, and less again on the experiences of these patients admitted to acute stroke wards. Like Chapter Two and Three, this study defines functional stroke patients as those patients who have not had a stroke and do not have any other medical aetiology for their symptoms but who may have a functional or psychological reason for their symptoms.

This chapter aimed to investigate and describe the attitudes and experiences of patients with unexplained stroke symptoms admitted to one HASU. We aimed to understand patients' experiences of symptom onset, the emotional and psychological effects of these admissions and to understand the role that patients' illness perceptions play in their admissions and symptom maintenance.

4.2 Methods

4.2.1 Brief Illness Perception questionnaire

The Brief-IPQ was completed with all participants at the end of each baseline and follow-up interview (Broadbent et al., 2006). Questionnaires were completed at participants' bedsides and via Skype at their two-month follow-up interview[5].

4.2.1.1 Questionnaire

The Brief-IPQ measures illness representations. The scale is derived from Leventhal's (1980) self-regulatory model which identifies five types of illness cognitions; consequences of being ill, timeline, personal control, treatment control and identity.

The scale has been used successfully in many illness populations including mental and behavioural disorders (Wiborg, 2015) and stroke (Sjölander et al., 2013). The questionnaire assesses illness perceptions on a 0-10 point Likert scale with higher scores indicating a stronger endorsement of that item. Sample items include, "*How much does your illness affect your life?*" and "*How concerned are you about your illness?*" (Broadbent et al., 2006). See "Appendix 4.1: Brief Illness Perception Questionnaire" for the questionnaire used in this study.

The last item assesses the person's view of the cause of the illness. This was not used in this study as it was a question explored in-depth within the qualitative interviews and one which a number of participants could not answer as they had not had formal discussions with their consultant at the time of the interview.

The questionnaire has good concurrent validity when compared to the Illness Perception Questionnaire-Revised and shows good test-retest reliability (Broadbent et al., 2006).

The questionnaire uses the word 'illness'. Due to the functional nature of participants' symptoms, 'illness' was not deemed a suitable term. Broadbent (2006) has noted that it is possible to replace the word 'illness' with the particular term of interest to the researcher while maintaining the questionnaire's psychometric properties. In this case, the term 'symptom' was used.

4.2.1.2 Survey analysis

An overall illness perception score was calculated for each participant. This represents the degree to which the illness is perceived as threatening or benign. To calculate this, scores on the 'personal control', 'treatment control' and 'coherence' items were reversed and added to

[5] Permission to use the survey was received from Elizabeth Broadbent.

the 'consequences', 'timeline', 'identity', 'concern' and 'emotional response' scores. A higher score reflects a more threatening view of the illness.

Repeated-measures Wilcoxon signed ranks tests compared the mean score of each item at baseline with the follow-up. These were used to investigate whether changes in illness perceptions from the baseline to follow-up assessments were statistically significant. *P*-values and confidence intervals were calculated. Cohen's *d* was also calculated to examine whether effect sizes were potentially clinically relevant. Analysis was completed using SPSS (IBM SPSS for Windows, Version 22, Chicago, SPSS Inc.)

4.2.2 Qualitative interviews

4.2.2.1 Qualitative interviews: setting

A handover meeting takes place at 8.30am each weekday morning on the HASU prior to the morning's ward round. This meeting is attended by all doctors working on the HASU. Occasionally the ward's matron or nurse consultant attends. At the diagnosis meeting, patients admitted to the hospital overnight are handed over to the clinical team by the night staff. Information on the handover includes their working diagnosis, symptom history, vascular risk factors, the results of any reports of diagnostic tests like ECGs, CTAs or MRIs as well as any remaining clinical tasks. Each patient is discussed by the clinical team.

Each day at 11 am the multidisciplinary therapy team meets. The progress of each patient is noted. These meetings are attended by the clinical psychologist, speech and language therapists, occupational therapists, physiotherapists, dieticians and often a junior doctor or registrar. Therapists discuss the progress of patients in relation to their movement, speech and functional outcomes such as their ability to cook, write, and the safety of their swallowing. Discharge decisions are often made at these meetings.

In addition to hyper acute stroke care, the ward also provides a TIA service and several weekly stroke clinics where patients are reviewed who have previously been discharged from the service.

With 15 beds on the ward, there can be up to 15 patients at any one time. Some patients came under the care of the stroke team but were located on different wards, for example in neurology. These patients were not approached for participation in this study.

A more extensive history of the HASU system is outlined in Chapter Three.

4.2.2.2 Qualitative interviews: procedure

Baseline qualitative interviews took place in the same HASU setting as the qualitative interviews with stroke staff outlined in Chapter Three. The researcher was embedded on this HASU from 18th January 2016 until 19th October 2016 and attended the 8.30am diagnostic morning meetings at the HASU ward each working day and the 11am multidisciplinary meeting (with the exception of public holidays and weekends).

Any patient with possible functional symptoms was identified from the handover sheet or by a clinician. The researcher spoke to the doctor to assess how likely the particular patient might be to have a functional explanation for their symptoms. The 11am meeting was also useful in discussing the potential diagnosis of individual patients.

The researcher discussed with the doctor whether it was possible to consent the patient into the study. In some cases, doctors advised this would not be feasible as the patients' diagnosis was unknown or there was likely a medical explanation for their symptoms.

If a patient was recently admitted to the ward, for example, the previous evening, they were often given an MRI that morning. The results of the MRI were usually known by between 2 and 3pm that day. If the MRI was clear, doctors often made the decision to discharge the patient immediately. In such cases, the researcher waited until the results of the MRI were known before approaching the patient. Patients were also included who had had a stroke but had 'functional overlay'; some symptoms that were not explained by stroke.

When stroke was definitively excluded by the team, and there was no other likely medical explanation for symptoms, the researcher approached the patient at their bedside. A description of the study was given and patients were asked if they consented to take part. An information and consent sheet was given. Interviews took place at their bedside. All interviews were recorded with a Dictaphone. Interviews were transcribed by the researcher. The transcription helped improve the researcher's familiarity with the data. See "Appendix 4.2 Information sheet for patients" and "Appendix 4.3: Consent sheet for patients" for a copy of the information and consent form used with participants.

Patients were also asked if they consented to be contacted in two months' time. All patients agreed. At the two-month follow-up date participants were phoned via Skype. At the follow-up stage, participants were again asked to give informed consent. All interviews were recorded.

Interviews took the form of semi-structured in-depth interviews and the interview schedule was devised by the study team. See "Appendix 4.4: Interview schedule for patients" for a copy

of the interview schedule used. Interviews were conducted in a non-judgemental, open style of questioning and participants were asked at the end of the interview to contribute anything extra they wished to add that had not yet been covered during the interview or to withdraw any information they had given that they did not wish to be included.

Of note, when approached by the researcher, patients often had had different types of conversations with the medical team or individual staff members. Some for instance had been told that there was no explanation for their symptoms, while others were awaiting an explanation. Due to this variability, the interviewer did not imply or bring up the functional nature of patients' symptoms but patients were asked what they believed caused their symptoms.

Patients were contacted via Skype two months after their baseline interview and the interview was conducted again. The same interview schedule was used in order to assess change over time.

4.2.2.3 Qualitative interviews: analysis

Baseline and follow-up interviews were analysed using a separate thematic analyses (Braun & Clarke, 2006). Data from interviews at both time points were coded and themed separately. The analytic approach here was the same as that taken in the analysis of clinicians' interviews. See Chapter Three, Section 3.2.4.3 for a detailed description of the approach used.

4.2.2.4 Qualitative interviews: ethical considerations

Ethical approval was granted by the Queen Square REC (15/LO/1914) on the 6th January 2016.

The study's recruitment began on the 18th January 2016. By the 15th February 2016, a slower recruitment rate than expected was noted and the process of applying for a non-substantial amendment from the Queen Square REC began. This application sought an extension of the recruitment period and was granted on the 24th February 2016.

There were a number of ethical considerations prior to the initiation of this study. Baseline interviews were conducted at the HASU bedside. As beds were on shared wards, to ensure privacy, each participant was offered a private room on the ward in which to conduct the interview if they wished. No participant took up this offer.

Each participant was asked to read the study information sheet. Participants were told that participation was voluntary and they could withdraw from the interview at any stage and that all information held was private and confidential. Once they understood the procedure and ethical implications, participants were asked to sign a consent sheet.

The follow-up interviews were conducted via telephone using Skype software. Participants were re-consented into the study. Consent was this time given verbally and consent sheets were signed by the researcher on behalf of the participants.

All baseline interviews were recorded with an encrypted Dictaphone. Participants were given a study ID and participants' names and contact information were stored on an encrypted spreadsheet with information stored in a locked file in a secure research unit. Any city names, person names or any other identifiable information was removed from the interview transcripts.

Other ethical dilemmas are inherent within qualitative research such as this. The researcher attended the doctors' diagnostic meetings and multidisciplinary staff meetings. Information on participants not in the study was commonly discussed. By attending these meetings, the researcher was party to conversations between doctors and clinicians about patients who later became participants in the study. In some instances, the researcher was aware of diagnostic test results before a doctor had conveyed that information to the patient. It was important in these cases that the researcher remained neutral throughout interviews.

By taking part in qualitative research, individuals can be given a voice, many of whom can find this therapeutic and beneficial. There is however also the possibility that such information, once published, can be used against certain groups or negative stereotypes can be reinforced (Finch, 1993). In the results of this study, a range of views are given to discuss each theme, rather than just the most common view, in the hope of avoiding simplistic generalisations.

It is increasingly common practice in qualitative research to involve participants in the analysis process (Tong et al., 2007), for example to return transcripts to participants for comment or correction or feedback on the results. While time constraints in this study rendered this difficult, some participants did agree that they would like to read the final version of this study when written and published.

4.3 Results

4.3.1 Participants

Over the ten months the researcher spent embedded on the hospital ward, 41 patients were considered as potential participants.

Six of these patients were discharged before the researcher could meet them at the bedside (for instance, they were admitted and discharged on the weekend or overnight). In each case the researcher attempted to contact them via telephone but was unable to reach them.

Three patients joined the study and were interviewed but were later excluded as they received a stroke diagnosis that explained their symptoms.

Two patients were approached but did not have capacity to consent to the study.

In total, 30 functional stroke patients were interviewed at baseline and 25 were interviewed at the two-month follow-up, giving a follow-up rate of 83.3%. The five participants who did not take part in follow-up interviews were uncontactable despite repeated attempts. Table 14 outlines the gender, age, ethnicity and occupation of participants as well as the symptoms with which they were referred.

Four participants (13%) had a history of previous stroke but after admission, no new stroke was found on their MRI scan. Two participants (6.7%) had confirmed stroke but their doctors believed their symptoms did not entirely correspond to their diagnostic tests and therefore some symptoms could be classified as 'functional overlay'.

Age data were known for 26 participants. The mean age of participants was 48.9 years of age (SD: 15.8). There were 22 females (73.3%) and 8 males (26.7%) in total. The most common ethnicity was white British (56.7%).

Baseline interviews took an average of 26.2 minutes (SD: 14.8 minutes) while follow-up interviews took on average 12.5 minutes (SD: 8.2 minutes)

The time between baseline and follow-up interviews varied depending on how easy it was to contact participants via Skype. The number of days set out in the study protocol between baseline and follow-up interviews was sixty-one, but it often proved difficult to contact participants after their discharge. In addition, there was only one researcher so interviews could be delayed due to holidays and bank holidays. The average number of days that passed between the baseline and follow-up questionnaire was 70 days (SD: 16.7).

Table 14 Sex, age, ethnicity, occupation and admission symptoms of qualitative participants

ID	Sex	Age	Ethnicity	Symptom	Occupation
1	M	NK	White British	Left sided facial weakness, left arm weakness	Medically retired
2	M	23	British	Expressive dysphasia	Business owner
3	F	29	Eastern European	Facial numbness	Waitress
4	F	20	Black British	Severe headache and dysarthria	Student
5	F	65	Black British	Frontal bilateral headache; right-sided pain & mild disequilibrium	Retired
6	M	56	White British	Left sided weakness and dysphasia. History of NES	Receives disability benefits
8	F	43	White British	Left-sided weakness and left visual disturbance and headache	Security firm consultant
9	M	67	British	Light-headed. History of previous stroke	Former carer, retired
10	F	NK	British	Left-sided pain	Stay at home mother
11	F	62	British	Rotatory vertigo, chronic fatigue and depression	Unemployed
12	M	53	White British	Left-sided facial droop and slurred speech	Employed, unknown
13	F	33	Pakistani	Dysphasia and headache	Office worker
14	F	64	Portuguese	Left hand numbness and expressive dysphasia	Retired teaching assistant
15	F	NK	Black British	Right sided weakness, headache, photophobia. History of bipolar disorder	NHS receptionist
16	F	21	British	Light-headed and syncope	Volunteer mental health researcher
17	F	88	British	Left-sided weakness. History of previous stroke. Possible functional overlay	Retired
18	M	NK	British	Reduced finger movements in both hands and muddled speech	Fire service officer
19	F	53	Jamaican	Sudden onset speech disturbance. History of anxiety	Old age carer in nursing home, on leave
20	F	31	White British	Left-sided weakness and facial droop	Special needs assistant
22	F	59	Black British	Left-sided weakness and numbness - previous stroke, symptoms indicate overlay	Unemployed
23	F	38	British	Migraine, left face and arm weakness. History of previous stroke and CFS	Church worker
24	F	52	Finish	Dysarthria, dysphasia, dizziness and posterior headache	Call centre worker
25	F	53	Black British	Left-sided weakness and frontal-post headache; multiple supra and infratentorial acute posterior circulation infarction with functional overlay	Nurse
26	M	50	White British	Left-sided weakness. History of depression	Unemployed
27	F	58	Iranian	Hyperventilation and shaking of upper and lower limbs following local dental anaesthetic	Engineer
28	M	55	British	Right-sided weakness. History of PTSD	Army officer, on medical leave
29	F	51	British	Left-facial droop and speech slurring	Child minder
30	F	49	Spanish	Left-sided headache, dizziness and diplopia. History of depression and fibromyalgia	Former cleaner, receives DLA
31	F	49	British	Left-facial weakness, dysarthria and left facial paraesthesia	Unemployed
33	F	51	German	Left-facial droop, left arm and face paraesthesia. Confirmed stroke with overlay	Psychotherapist

M = male; F = female, NK = Not known

Two participants did not complete a Brief-IPQ at baseline or at follow-up. In total there were 28 baseline questionnaires and 23 follow-up responses. The follow-up response rate was 82.1%.

Of the 28 questionnaire responders, 20 (71.4%) were female and 8 were male (28.6%). Age data were available for 26 participants. The average age was 48.9 (SD: 15.8).

The age and gender of respondents who completed only one survey was compared to those who completed the survey at both baseline and follow-up. There were no statistical differences in the gender profile of either group. Those who completed only one survey were slightly younger than those who completed two but no statistical difference was found (mean age: 47 years (SD: 15.8) versus 49.4 years, (SD: 16.2), $t = 0.30$, $p = 0.77$). Table 15 outlines the age and gender profile of participants who completed both baseline and follow-up questionnaires with those who completed only one questionnaire.

Table 15 Age and gender profile of Brief-IPQ survey completers versus those that completed one or no survey

	All survey respondents n (%)	Completed both surveys n (%)	Completed one survey n (%)	*p* value*
Total	28 (100)	23 (82.1)	5 (17.9)	
Female[1]	20 (71.4)	16 (69.6)	4 (80)	> 0.05
Male[1]	8 (28.6)	7 (30.4)	1 (20)	> 0.05
Mean age (SD)[2]	48.9 (15.8)	49.4 (16.2)	47 (15.8)	> 0.05

*comparison between those completing both surveys with those completing only one
[1] Chi-square test
[2] *t*-test

4.3.2 Brief Illness Perception questionnaire results

The mean total Brief-IPQ score at baseline was 49.3 (SD: 9.9) and at two-months' follow-up the score reduced to 39 (SD: 20.1) suggesting participants' perceptions of their symptoms went from being seen as threatening to more benign with time (total possible score: 80). Males and females did not differ in their scores at baseline or at follow-up.

Higher values imply worse outcomes. The highest mean scores at baseline were the 'emotional response' item (mean 7.8, SD: 2.6) and 'concern' regarding symptoms (mean: 8.2, SD: 1.8). Lowest mean scores were for perceptions of treatment control (mean: 2.9, SD: 3.2) suggesting participants were emotionally affected and concerned by their admission but relatively optimistic that treatment would help. Table 16 outlines baseline and follow-up mean scores for each item and change over time.

Two months later all mean scores had dropped. The highest score was now personal control (mean: 5.9, SD: 3.9) and the lowest was treatment control (mean: 2.5, SD: 3), suggesting participants felt they did not have personal control over their symptoms but believed the treatment they received could help.

Repeated-measures analyses were conducted to assess changes in mean scores over time. 'Consequences', the self-reported effect of symptoms on the person's life (Z = -3.4, *p* = 0.001), 'identity' denoting the number of symptoms a person experienced (*Z*= -2.1, *p* = 0.04), 'concern' (Z = -2.7, *p* = 0.01), and the mean 'emotional response' (Z = -2.0, *p* = 0.05) saw a significant decrease in scores over time. There was no statistically significant change in responses to the 'timeline' question (how long they expected to experience symptoms), the degree of personal control patients felt they had over symptoms, the degree to which they believed treatment might help their symptoms or how much patients felt they understood their symptoms. The disparity in the gender ratio of participants did not allow for gender to be accounted for in this study.

Table 16 Changes in Brief-IPQ results between baseline and follow-up

	Baseline mean (SD)	Follow-up mean (SD)	Wilcoxon signed ranks *Z*	*p* value	*d*
Consequences	7.33 (2.8)	3.3 (3.6)	-3.4	**0.001**	1.25
Timeline[1]	5.83 (2.9)	5.2 (4.3)	0.42	0.68	0.18
Personal control	7 (3.4)	6.2 (4.1)	-0.49	0.62	0.21
Treatment control	2.9 (3.4)	2.2 (3.1)	-0.85	0.39	0.22
Identity	4.95 (2.9)	3.5 (3.6)	-2.1	**0.04**	0.44
Concern	8.2 (1.8)	5.6 (4)	-2.7	**0.01**	0.84
Understanding	5.2 (3.7)	4.9 (4.6)	-0.47	0.64	0.07
Emotional response	7.8 (2.6)	5.6 (3.7)	-2.0	**0.05**	0.69

[1] Normally distributed data so statistic reported here is a *t*-test
Scores range from 0 to 10. A higher score indicates a more negative response
Cohen's *d*: very small: 0.01; small: 0.2; medium: 0.5; large: 0.8; very large: 1.2

4.3.3 Baseline qualitative interview results

The results of global themes from the baseline interviews are presented in Table 17.

Table 17 Thematic framework derived from baseline qualitative interviews

		Global themes	
	'Phenomenological experiences'	'Symptom attributions'	'Views on the future'
Thematic families	Symptom onset & experience	Common attributions	Views on recovery
	Help-seeking	Locus of control	Attitudes to research
	Inpatient experience	Authenticity	Views on treatment
	Emotional response		

Three global themes emerged with corresponding sub-themes. The first theme relates to phenomenological experiences such as symptom onset, admission and inpatient experiences, and emotional reactions. The second theme deals with symptom attributions; the common attributions made by staff, perceptions of control, and the issue of authenticity. The third and final theme deals with issues related to patients' future; their views of recovery, attitudes to research and views on treatment. The final section explores results from the follow-up interviews and the themes of symptom experience and attributions.

4.3.3.1 Phenomenological experiences

4.3.3.1.1 Symptom onset and experience

Two distinct types of symptom onset occurred. In the first type, participants experienced a sudden onset of somatic symptoms that seemed to occur without warning. The second type was inconspicuous and more dissociative in nature, i.e. the feeling of altered awareness.

The patients who experienced a sudden onset of somatic symptoms described a range of everyday activities they were engaged in when their symptoms began. Symptoms were unexpected, often disturbing and often were accompanied by sensations of panic. These symptoms represented an abrupt interruption to everyday life:

> *"I was just on the underground. And, I, it was just a normal day really. I felt fine the whole day. Yeah, and I just started to lose, my vision started going...I just wasn't with it. I felt really ill and then my speech was going"* (Participant 2, male, 23)

> "*I was in a bus. And I suddenly couldn't remember where I was going or what bus I was on, 'I can't remember what I'm meant to be doing'"* (Participant 15, female)

Memory failure was mentioned by another participant who described being unable to recall what had happened prior to his admission and found this inability disconcerting:

> *"I collapsed whilst I was in the toilet…It's disturbing. It's frightening not knowing what I have or haven't done. What makes it worse, because it happened in the pub, I don't know whether I've upset anyone, or what, to be quite honest"* (Participant 1, male)

Panic was a frequent response to symptom onset:

> *"I couldn't lift my arms, I couldn't lift my fingers, I couldn't lift up my head…by then I was panicking so I started to cry. Even that was an effort"* (Participant 15, female)

Another participant acknowledged the possibility that the panic itself might have served to worsen her symptoms:

> *"It lasted about one hour. It was not very, it was a slight sensation, maybe because I became panic-y as well"* (Participant 14, Female, 64)

Five participants described how their symptoms began while commuting. Being in crowds seemed to be at least a partial mediator in the experience of panic. Feelings of agoraphobia on public transport could serve to worsen already existing symptoms or promote misinterpretation and an intense focus on physical sensations which could lead to the emergence of somatisation (Tomasson et al., 1991). There can be unpleasant consequences to experiencing such symptoms while travelling. Being away from home, feeling ridiculed, or unable to ask for help could intensify already existing symptoms and anxiety. Being surrounded by people could be also prove useful as a number of participants described how other passengers called for medical help.

While the circumstances in which symptoms began varied, there were a variety of symptom types. These ranged from dizziness, disorientation, weakness, numbness, pain, visual disturbance, headache, memory disturbance, changes to or the loss of speech, fatigue and facial droop (see Table 14 for a list of symptoms).

The second type of symptom onset represented a more insidious onset, one marked by a shift in phenomenological experience, often characterised by discomfort and which frequently had dissociative qualities which could feel strange and unusual. This type of experience seemed to have a less well defined onset:

> *"I couldn't talk. My legs were feeling jelly-ish. I couldn't walk. I was stumbling. I had to hold walls to walk. My arms had no coordination. I was slurring. You could not understand what I was saying"* (Participant 13, female, 33)

> *"I was beginning to feel very fuzzy headed. You know, it was sort of as if I'd had a good drink. It wasn't like a pounding headache, I was getting like a…it sounded like going*

> *through my head, the sea. When you pick a seashell up off the beach and put it to your ear, you hear the sea and that was what I was feeling in my head…I felt a bit drained. I decided to go to bed"* (Participant 9, male, 67).

Other participants also likened the experience to being drunk:

> *"I felt as though I was drunk. Apart from my head. My head felt ok but my body wasn't responding. And I felt as though I was being enclosed in my body"* (Participant 18, male)

Dissociative processes may help explain these experiences (Spitzer et al., 1999). A large study of NES patients found over 60% experienced depersonalisation and derealisation immediately before, during or after the attacks. Symptoms in this study included shortness of breath, dizziness, sweating, heart palpitations amongst others (Hendrickson et al., 2014). In our study, patients who experienced these symptoms often did not seek immediate help. These symptoms, while strange, were not experienced acutely and did not seem to be particularly painful. One participant who commonly suffered from headache did not feel immediately concerned by the experience and did not seek immediate help:

> "*My head was hurting but I thought it was just a normal headache so I didn't think to alert anyone. I didn't take any medications. All I done was went to sleep"* (Participant 4, female, 20)

This lack of concern, or potential 'la belle indifference', was similarly described by a male participant who resisted the urge to phone for help and believed it was something he could control and treat himself:

> *"I had a couple of beers. I was lying on the sofa and then I woke up at two in the morning. I was lying on the floor. I couldn't move my side. I couldn't swallow. And I just thought it was something brief so I just thought, 'I'll just carry on' and I thought 'I can heal myself' if you like because I started doing weights with my hand. And I went on for, like, three weeks"* (Participant 26, male, 50)

The types of symptoms themselves appear to affect one or many neurological functions and ranged from distinct deficits like weakness or visual disturbance through to amorphous and strange experiences which appeared to represent an experiential interruption to everyday life. When symptoms occurred unexpectedly and acutely, they caused distress and panic.

Slower, more inconspicuous onsets were associated with dissociative experiences and might tentatively be associated with 'la belle indifference'. Nonetheless, it is important to note

however that la belle indifference is a term usually used by clinicians to describe a patient's attitude rather than a subjective experience. It has previously been reported in approximately 21% of functional patients' presentations but it has not been shown to be a clinically useful sign (Stone et al., 2006).

The symptom onset described in this study align closely with that reported by Stone et al. (2012b) in patients with functional weakness recruited from a neurology service in Scotland. This study categorised three distinct modes of onset including sudden (accounting for 46% of the group), present on waking (13%) and a gradual onset (39%).

4.3.3.1.2 Help-seeking

How participants experienced the onset of the symptom was mediated by the kind of help they received from those around them at the time. Having symptoms taken seriously by others was important, but this might have served to reinforce feelings of panic and concern. One participant described realising that his symptoms might be stroke only after an ambulance driver made a stroke assessment:

> *"A couple of minutes later the ambulance crew turned up. I heard the handover, 'He's FAST negative' so I know that now he is checking for stroke and the signs and symptoms of normal stroke are negative. I got into the ambulance and they said, 'We're going to take you to the hospital for precaution'. I felt very silly, very upset, very emotional*" (Participant 18, male)

While receiving help could be anxiety-provoking, for some, the perception of not being taken seriously at the time of symptom onset was also worrying. Some participants described not being taken sufficiently seriously by ambulance crew and medics. This may have led to concern that they wouldn't receive appropriate treatment and their symptoms would get worse:

> *"Somebody called an ambulance and the first responder came. He was as helpful as a lump of coal. And, that experience, I wanted to throttle him. Because he was like, 'How are you feeling?' and I was like, 'Listen, how is this going to help me? I don't think I can hold my head up much longer.' And the next thing I knew I was on the floor. I couldn't lift my arms. I couldn't lift my fingers. I couldn't lift up my head"* (Participant 15, female)

In some cases, the act of seeking help seemed to reinforce or intensify the experience of symptoms. In a number of instances, while trying to outline and describe their experience to

an ambulance worker or emergency call worker, participants' symptoms intensified or worsened and in some cases they were unable to communicate at all:

> *"*[The paramedic] *did some tests. He called the ambulance. He said, 'Because something's not right. You're not. I can see you're not right and I'm not finding anything in the normal realm of things that would tell me why'. And then the ambulance crew came and it got more and more difficult to concentrate and keep my speech fluid…I don't know…I don't really do panic, you know?"* (Participant 8, female, 43)

It is possible that when receiving help, the self-reflection and concentration needed to focus on the symptom, recall its onset and describe the somatic symptoms was in itself anxiety-provoking and upsetting:

> *"So I'm on the phone with my son. I feel different in my body. I feel sick. I said to my son, 'I don't like how I feel, I'm going to call '111' and speak to them'…The doctor did call and I'm explaining what happened. He was saying he should send a doctor or an ambulance out. I'm saying, 'Send a doctor out please'. And I feel a terrible pain come down sharp, come down my neck"* (Participant 19, female, 53).

Help-seeking is an inherently social act and it is likely that the initial response of friends, family and medics to the patient may influence the experience of the symptoms themselves.

4.3.3.1.3 Inpatient experience

Most participants described a swift admission to the HASU. There was often a short waiting period in an emergency room but most had scans almost immediately after their arrival and in some cases they were also thrombolysed. A sense of urgency from staff characterised their initial experiences on the stroke ward:

> *"*[The ambulance] *brought me here right away. When I arrived they saw me straight away, after five minutes or so and after the scan and everything, they sent me here"* (Participant 14, female 64)

One participant describes being left alone briefly before the stroke team descended and their care escalated:

> *"I was in a hallway. A nurse came and took some bloods and I thought, 'Well, where are the people?' All of a sudden and it got, all, very hectic and all, 'Oh my god' and then I knew it must be a stroke because they are all talking about the 'window' and I knew*

> *about the blood clotting stuff…so it was then clear to me what was going on. (*Participant 33, female, 51)

During this period participants described feeling confused by the tests and believed the medical team were also confused. He describes receiving mixed messages regarding his possible diagnosis:

> *"I remember meeting doctors and them trying to get me to do things, like different tests and they weren't sure what was happening. They weren't sure what it was and then they said, 'You've had a stroke' or 'You've had a minor stroke' or something like that"* (Participant 2, male, 21)

It is possible that the urgency and effort in trying to diagnose and treat the presumed stroke reinforces or contributes to beliefs that symptoms have a physical explanation which may escalate existing panic or worry. Once stroke has been ruled out however, the sense of urgency abated and some patients begin to feel less like a clinical priority:

> *"There are some, very focused, very clever, but neurology-only doctors, where I think they sort of want to send you out because you're not dying…I felt a bit patronised"* (Participant 33, female, 51)

It may be at this juncture the relationship between the patient and staff becomes problematic. Feeling like an uninteresting patient is not uncommon for patients with unexplained symptoms. A similar sentiment was described by men living with unexplained pain who described how clinicians lost patience and interest once a physical cause was not found (Paulson et al., 2002). Such concerns are likely not unfounded as doctors themselves often describe their lack of interest in these patients (Garcia-Campayo, 1998).

4.3.3.1.4 Emotional response

Patients experienced a variety of symptoms and a range of emotional reactions in response to these symptoms. Patients' emotional responses differed depending on the kind of interactions they had had prior to their admission or once on the ward.

Most participants described feeling worried, fearful or upset during their admission. Some were articulate and insightful when describing their emotional response and they were often aware of their own ability to control their emotions. For others, emotions felt overwhelming and unbound, a reaction over which they did not feel they could exercise any control.

Some participants describe feeling more emotionally labile in the run up to their admission:

> *"I seem to get upset, I don't know whether it's this or not, but I get upset very easily recently, over the silliest little things that before wouldn't have bothered me"* (Participant 11, female, 62)

The experience on the ward itself was most often characterised by feeling anxious and upset:

> *"Just depressed. It makes me feel sad and depressed"* (Participant 27, female 58).

Another participant, who had had a stroke but experienced additional functional overlay, described how the experience on the ward had been disturbing due to being exposed to people with serious illness:

> *"There were three old women there* [on the ward] *and one of them was sort of on death's door and I found that hugely distressing because she was screaming all the time…I could hear everything and I just felt myself getting more and more anxious and going downhill"* (Participant 33, female, 51)

These negative emotional experiences were echoed by other participants:

> *"It makes me quite irritable. I don't like to say angry, but it makes me feel angry"* (Participant 17, Female, 88)

> *"There is of course some underlying anger about it, 'Why me?'"* (Participant 24, female, 52)

> *"After this happened, I'm very disappointed and now I'm very depressed"* (Participant 10, female)

Stoicism was also commonly expressed:

> *"All I'm concentrating on is happy thoughts and things that make me happy"* (Participant 22, female, 59)

> *"You can't sit there and bawl your eyes out"* (Participant 18, male)

> *"They send me home not knowing what's gone on but there's still a bit of tingling and weakness. I'm just going to have to take it in my stride"* (Participant 22, female, 59)

These stoical responses serve to highlight the extent of the emotional impact of the experience itself. While negative emotions were experienced as something beyond the patient's control, stoicism was a coping strategy employed to deal with the severity of the emotions experienced and a tool with which to become more optimistic about the future.

Participants described other attempts to control their emotional responses. One of the participants gave a multifaceted account of her emotional response:

> *"There are certain things which, unless you can think your way around them, are going to take their toll in a more comprehensive way than others…I have to say the biggest part, the most destructive part for me was guilt. You know, 'I've got absolutely no right to be feeling like this. Why am I feeling like this?'"* (Participant 8, female, 43)

Another participant with stroke and functional overlay described how she would first deal with her physical symptoms before trying to tackle the emotion by her diagnosis:

> *"I deal with the physical symptoms first and then at some point it will filter through…When you have anxiety, you're anxious… but at least I recognise a bit more what I'm doing with it and know that I'm pushing it to one side because I have to, but I have to concentrate on the other side first"* (Participant 33, female, 51)

Participants who had no stroke aetiology expressed relief when told they had not had a stroke:

> *"I was very relieved. Because what I didn't realise was the impact of having had a stroke. This sounds silly, not just on my body, but also the repercussions for me as an individual, sort of things like driving restrictions"* (Participant 18, male)

> *"Happy that it's not anything serious"* (Participant 20, female, 31)

While some participants were relieved, others were concerned that they had not received a positive diagnosis and were left wondering what had in fact caused their symptoms. As one participant described:

> *"I take the positive and tend to take the middle road and if it gets sorted then it's going to be brilliant, but if they don't find out what is causing it and then I just have to put up with this, then I won't be happy"* (Participant 29, male, 55)

This point was reiterated by another participant who argued that not knowing what caused his symptoms was more worrying than receiving a concrete diagnosis:

> *"They said* [the medical team] *'You were lucky, it was nothing'. Yeah, I'm lucky it was nothing, but who wants that answer?"* (Participant 27, female, 58)

Participants react to their admission with fear, worry and mood lability. Some described coping styles such as stoicism in response to the belief they had experienced a stroke. For those who knew there was no underlying stroke aetiology, participants tended to either express relief they had not had a stroke or worry that there was another potential cause for their symptoms.

4.3.3.2 Symptom attributions

4.3.3.2.1 Common attributions

When participants were asked what they believed caused their symptoms, not unlike the stroke clinicians' responses in Chapter Three, their responses ranged from uncertainty to mentioning potential biological, psychological and social causes. Many of the views expressed were mediated by the kind of conversations participants had had at the bedside with their stroke physician prior to the interview. Participants, not surprisingly, aligned their attributions with what they had been told by the doctor.

Frequently, doctors had told participants that they were unsure about symptom aetiology, and participants, in turn, said that they did not know what had caused their symptoms. Amongst these responses was a pervasive sense of confusion:

> *"I'm still not convinced that I've had a stroke of any kind. And it's very confusing. Some say I have and some say I haven't…"* (Participant 8, female, 43)

> *"The MRI showed up fine, everything showed up fine…they just kind of said they don't think it's a stroke, it could have been a small stroke but they don't think that it is. They don't know what it is. And that was a little bit worrying…They didn't tell me anything they could do really. They didn't suggest anything else"* (Participant 2, male, 23)

> *"I said, 'What happened then? It must be something' because I've never, I've never witnessed that before. She* [the nurse] *said she don't know…They did some scanning. They said they're going to do an MRI. I had no doctor come back to me to say, 'Well, it's not a stroke but it's…whatever' because it must be something, causing that"* (Participant 19, female, 53)

The uncertainty and lack of concrete information was uncomfortable for patients and some described feeling uneasy due to the lack of information they had been given:

> *"Don't ask me why. I don't know why. I'm the kind of person that likes to know if it is one thing or another. Not in between…I'd rather they said it, come out straight with it"* (Participant 11, female, 62)

> *"They don't know what's causing the symptoms so I'm going home without any information and that doesn't make me feel confident"* (Participant 22, female, 59)

One participant described how the lack of a formal diagnosis meant that her treatment options were limited:

> *"First of all, I was relieved that it is nothing very serious. Second, not relieved because I would like to know what's causing all this. Because if the cause is clear and known, then there is at least a chance that there would be a treatment or preventative treatment that would keep it at bay, whatever it is"* (Participant 24, female, 52)

Some participants had beliefs about the cause of their symptom but felt their knowledge was limited:

> *"You understand to a certain extent what is going on, but you don't really know why. Do you know what I mean, because you know that you're feeling unwell and it frustrates you a bit when you come to hospital, where you can't stick a sticky plaster on and say, 'All better'"* (Participant 9, male, 67)

Uncertainty was not the only response. Two participants believed there was a potential biological cause for their symptoms but were unclear as to whether the symptoms themselves were stroke or not. One participant believed her symptoms might be the result of side-effects from antibiotics while another felt it might be linked to weight. The assumption of an underlying biological explanation is implicit here:

> *"Well, I'm overweight…I'm still not sure why this happened. With my hands* [referring to numbness] *there's a suggestion it could be a virus. It could be carpel tunnel, they're not sure"* (Participant 18, male)

Psychological and psychosocial accounts of symptoms were common but beliefs about whether the symptoms themselves were stroke or not were rarely clear. Participants frequently suggested potential psychological stressors like anxiety were a potential causal factor, but were unclear about their beliefs regarding the aetiology of their symptoms:

> *"It can be stress because I heard news about my dad's* [sickness] *so maybe I was thinking too much. So they were saying it can be stress"* (Participant 3, female, 29)

The possibility of a psychological cause was echoed by another participant who felt her symptoms could be attributed to a busy life with many responsibilities:

> *"I've just got a lot going on in my personal life. A lot of major milestones. Children doing important exams, getting married…so all those things at once, has just caused a huge amount of stress"* (Participant 29, Female, 51)

Another participant attributed his symptoms, or at least the worsening of symptoms, to a recent bereavement:

> *"My condition overall I think might have been a bit, how do you say, exasperated by the fact my wife passed away last May"* (Participant 9, male, 67)

Another participant rejected a psychosocial account, but did not have any defined views on an alternative cause:

> *"My mum thinks that I was stressing because of my exam results but I wasn't stressing. I'm a very positive and happy person so nothing comes to mind. I wouldn't want to be sick right now. It's very sunny outside"* (Participant 4, female, 20)

While these quotes highlight the acknowledgment by patients that psychological factors may play a part in the expression of their symptoms, it was unclear whether participants believed psychological factors were the entire explanatory cause of their symptoms or whether psychological problems were a moderating factor, partially contributing to the onset of an actual organic stroke.

Another participant, for instance, described how psychological factors helped moderate a biological trigger which led to the onset of an organic stroke. She did not however believe that her physical symptoms were themselves psychological:

> *"I'm assuming it could just be all the stress building up and then the stroke"* (Participant 13, female, 33)

Another participant was strongly convinced that psychological factors had not caused her stroke, but rather the stroke had caused psychological symptoms:

> *"He said* [referring to an ambulance worker] *'Oh she's just upset, once she calms down she'll be able to get up...sometimes when young people are upset, they just collapse'. And I'm trying to say, 'I didn't collapse because I'm upset, I collapsed because I got upset after I collapsed'"* (Participant 15, female)

In summary, patients make a number of attributions from identifying biological to psychosocial causes like anxiety, stress and external social factors like family life. Commonly participants are uncertain about the cause of their symptoms, a fact reflected by the lack of information participants receive from their clinicians. While some participants mention the role of emotional and psychological factors, causal accounts and pathways are difficult to disentangle.

4.3.3.2.2 Locus of control

Locus of control is the degree to which a person attributes events and actions in their life to internal factors such as their own behaviour or ability, as opposed to external factors like chance or the environment.

Almost uniformly, participants believed they had no control over the course of their symptoms:

> *"I didn't have control. Like it happened and that's it"* (Participant 3, female, 29)

While participants often felt they did not have control over symptom onset, similar to their emotional responses, some believed that they might have control over symptom progression:

> "*One doesn't really have control over symptoms. One has control over the reduction of symptoms"* (Participant 8, female, 43)

Linked to this sense of a lack of control was a degree of fatalism or at least resignation. Maintaining an external locus of control regarding the onset of the symptoms could be a means of protecting oneself psychologically, avoiding self-blame and helping to reduce any tendency to engage in counter-factual thinking. This may be a manifestation of the stoicism described earlier. In this particular instance, the participant had had a previous stroke but after admission, no new stroke was found:

> *"These things happen and you can't alter it. So in that sense I find that I don't have control"* (Participant 17, female, 88)

Participants felt they had some control regarding their future preventative behaviour, and mentioned taking approaches like taking more trips to the doctor, taking the correct medication and losing weight as ways in which they might prevent a re-occurrence of symptoms. Others described how they would not try to change their health behaviour as symptoms were beyond their control:

> *"Whatever is causing it is nothing I'm doing. I'm not going to fret about it. I will simply stick to my medical regime and hope for the best because I'm not going to worry about something I can't change"* (Participant 24, female, 52)

Another participant mentioned his family history as the reason she had so little control over symptoms. For this participant, lifestyle changes were the best way of controlling the symptoms:

> *"My dad died with a heart attack and my mum with stroke. Cerebral stroke. But there is nothing that I can do. Like I feel now that the best way is to take more care of myself which is what I've been trying"* (Participant 14, female, 64)

A lack of internal locus of control is therefore pervasive throughout these interviews and echoes our findings from the Brief-IPQ.

4.3.3.2.3 Authenticity

While participants felt that the onset of their symptoms was been beyond their control, a small number expressed worry that clinical staff believed their symptoms were volitional and were concerned that they might be viewed as malingerers or as performing symptoms for some gain:

> *"I was very angry at first because it's as if you're putting it on and wasting people's time but I'm not that sort of person. I don't like hospitals"* (Participant 6, male, 56)

Another participant felt judged by staff and that they were not deserving of treatment:

> *"I feel like if I call them to say something to them, I feel like I'm bothering them"* (Participant 19, female, 53)

Participants are concerned that the legitimacy of their experiences was questioned by staff. Throughout interviews, participants expressed concern that their motivations might be misconstrued and were concerned that their experiences might be undermined, denied or dismissed:

> *"I feel like a bit of a fraud sitting here"* (Participant, 11, female, 62)

> *"People think that, 'Oh, he's had the medical book out, what page is he on today? What does he have wrong today?'…they think you're a pest at hospitals…you're just pestering people and you're looking for something that is not really there. You're not having the confidence in what the doctors are telling you. And you feel as though, oh, 'They're going to get fed up with me' You know? 'They're going to blacklist me'"* (Participant 9, male, 67)

Another participant felt frustrated and worried that she was being judged for wasting time and resources:

> *"It's frustrating…when I get any type of treatment and they're saying, 'Oh, she doesn't want to work' but people who know me know that that's not true because I work very hard"* (Participant 19, female, 53)

This fear of judgement is pervasive throughout interviews and participants are particularly concerned that they will be viewed as illegitimate recipients of care.

4.3.3.3 Views on the future

4.3.3.3.1 Views on recovery

While on the stroke ward, participants had varied opinions on life once discharged. While some participants' symptoms abated during their admission, they were nonetheless concerned that symptoms might return in the future:

> *"I'm so scared it's going to happen a second time and a third time"* (Participant 3, female, 29)

> *"I don't feel a thing, but I can't say if the symptoms will come back. They could come back next week. I don't know"* (Participant 13, female, 33)

> *"It could have been worse, but you know, the doctors can't tell me if it is going to happen again. There's a likelihood of it happening again. They've done all the investigations which shows up okay, but in the future they don't know"* (Participant 25, female, 53)

This concern about the future and the difficulty in coping with uncertainty was made more acute by a fear that their ability to work might be restricted. This worry about potentially losing their livelihood was a source of distress:

> *"I don't want to be disabled like this. I am very active with my kids and I'm new here* [to England] *and I want to start my life. I don't want to lose work"* (Participant 10, female)

> *"I'm just hoping that this doesn't continue and I can come out of here and go back to work the next day and carry on as before. That's what I'm really hoping for"* (Participant 15, female)

> *"I'm extremely concerned because I have to work. If I am not working, I am not earning. I have to work. So that is extremely concerning about my health…I'm working as a contractor. One important meeting, I lost it. And no one is bothered about that* [stroke staff]" (Participant 27, female, 58)

This point regarding participants' concern about their employment status is worth reiterating. Some clinicians interviewed in Chapter Three expressed the view that patients might be wilfully producing symptoms in an effort to avoid work or gain benefits. These quotes highlight that at least a proportion of participants are in fact keen to work and work appears to be important to their identity and self-worth.

A number of participants were hopeful that if they made lifestyle changes, their symptoms might improve and they would make a full recovery. It is likely that these views emerge from biological causal attributions:

> *"If I can get the physio in and get moving I think I might be able to get going again"* (Participant 22, female, 59)

> *"If I change my lifestyle completely. I think that will help. Get my blood pressure down, although I take blood pressure medication, I take diabetes medication but I think in terms of eating and exercise…"* (Participant 25, female, 53)

Regardless of whether patients believe their symptoms were caused by biological or psychosocial factors, expressing the view that their symptoms might respond to lifestyle changes highlights a certain degree of control that patients feel over their symptoms, something that they were often unwilling to admit when asked directly.

4.3.3.3.2 Views on research

One of the original purposes of this study was to gauge participants' views on taking part in research generally and physiotherapy specifically.

All of the participants were happy to be involved in research but gave different reasons. Some felt that taking part in a physiotherapy trial would directly benefit them:

> *"I would be happy to take part in and do that because whatever it takes to get me back on my feet"* (Participant 19, female, 53)

Another participant felt that the social nature of being involved in research might be beneficial in itself:

> *"We could as a group, as a club, we could exchange views and ideas and problems, all that"* (Participant 9, male, 67)

Some believed there was an innate pedagogical value to taking part in research:

> *"I'm a big proponent of learning hospitals and learning in general so if there's anything I can do, I'll always jump in"* (Participant 8, female, 43)

Altruistic reasoning was also evident in other participants' responses:

> *"It may not necessarily help me, but if it's going to help others in the future and maybe a learning basis on both sides of the coin"* (Participant 9, male, 67)

> *"If my experiences can help somebody else, that would be really great"* (Participant 24, female 52)

Others felt that answering the semi-structured interviews had in itself been beneficial in helping patients examine their own personal response to their admission when they hadn't had an opportunity to do so previously:

> *"It's really helpful to go through these questions, realise myself how I'm thinking and how I'm feeling because I don't, I don't stop and go, 'How do I think about this?'"* (Participant 26, male, 50)

> *"It does help, talking to other people. If it's not family. I think it's important to share these things because if you bottle them up inside, it's like a bomb waiting to explode. And there's not many people you can talk to about it, you can't talk to your own wife"* (Participant 6, male, 56)

Most participants agreed that they would be happy to travel to take part in research. Some expressed a preference for engaging in research in their home but another participant saw a benefit in travel in itself:

> *"I don't mind travelling. It would get me out, wouldn't it?"* (Participant 11, female, 62)

Asked whether they would be willing to wait to receive an intervention, for example if they were randomised to a waiting arm of a trial, some said they would still take part, provided they still needed the intervention while others expressed a preference for such an intervention to start immediately.

4.3.3.3.3 Views on an ideal treatment

Participants were asked whether they would be happy to try physiotherapy as an intervention. Although some participants did not have symptoms that might directly respond to physiotherapy, they often had other somatic symptoms that they believed would benefit.

> *"To strengthen my limbs…If I can get the physio in and get moving I think I might be able to get going again"* (Participant 22, female, 59)

The non-specific benefits of physiotherapy tended to be acknowledged by participants rather than the specific features of the therapy. As one participant noted:

> *"So physio, I don't mind because if it's going to help to rehabilitate me, of course, I'm interested in it. So something like that, or maybe talking about your experience"* (Participant 15, female)

Another participant mentioned the possible benefits of talking therapy:

> *"My motor function wasn't affected at all, only my senses. I would like some sort of help with how to manage that, how to think about it…if there is anything I can do to make it better, if I just, if I know I just have to be patient then I just have to be patient, but I don't want to miss a chance, if I can do something"* (Participant 33, female, 51)

Patients describe a will to get better and are open to physiotherapy or any other intervention to try to improve.

4.3.4 Two-month follow-up interview results

Follow-up interviews were completed two months after the baseline HASU interview. This section discusses the changes over time in symptom experience and attributions.

4.3.4.1 Symptom experience

Two months after their discharge from the HASU, participants' symptoms had remitted completely, partially improved or they continued to experience symptoms with some new symptoms emerging. Information on symptom progression was available for 25 participants of whom 10 (40%) saw no improvement, 4 (16%) saw partial improvements and 11 (44%) saw improvements in their symptoms or a complete resolution.

Patients who no longer experienced symptoms tended not only to describe their symptom remission but an overall improvement in their general health also. This improvement likely occurred because participants became more health conscious and made lifestyle changes:

> *"I feel fine. I play tennis every week and I run so I kind of, that's keeping me as fit as I can. I mean, to be honest, if something is going to happen to me, something is going to happen to me so I kind of work on that basis and just carry on as normal"* (Participant 12, male, 53)

Others had seen an improvement in their initial symptoms and the emotional intensity which accompanied the symptoms had dissipated:

> *"I can do more. When I first left hospital I was almost bed ridden, I was so tired. I developed a headache, I felt tired, I felt dizziness, my balance was out of kilt, a whole ream of things. Definitely, over time, I can do more. I can actually go to the bus. I can work…before I used to get anxious…and I was speaking to the nurse about a problem, I would fall down. I'm feeling better, more active"* (Participant 23, female 38)

The group who continued to experience residual symptoms found these symptoms difficult to expunge:

> *"The migraines started before I was in hospital and they haven't stopped to date and medication that I have tried hasn't worked and I've tried different ones so far"* (Participant 15, female)

> *"My mouth is shaking. I've got tingling down the side of my head"* (Participant 31, female, 49)

> *"My head goes really funny, I get a really bad headache, I feel sick, I start struggling to breathe. Whether that's stress or anxiety, I don't know and then I feel really dizzy…that lasts for about ten minutes and I go into seizure. All I know is that it's pretty violent, that's all I've been told"* (Participant 16, female, 21)

For some of this group, they went on to develop new somatic symptoms. These symptoms may be functional, but it is also possible that being admitted to hospital had enabled the detection and diagnosis of other underlying health problems. One participant described being referred for memory problems:

> *"I'm going to see my GP this week because the consultant that I saw said he's going to make a few recommendations plus I had seen a mental health nurse earlier because my memory was a bit shoddy at best"* (Participant 15, female)

4.3.4.2 Symptom attribution

At the baseline interview, most participants were confused about their symptom onset and were unable to account for a possible cause. Of patients who held causal explanations, many believed they had experienced some kind of stroke event. Some participants believed that anxiety or psychological factors may have played a role, but were unclear about the exact

causal mechanisms and it was often hard to ascertain whether they viewed these factors as directly causal, or as moderators of their symptoms.

Two months later, the majority of participants had been told definitively that they had not suffered a stroke via a GP referral letter or in a follow-up stroke clinic. Not having had a stroke was something most accepted and most expressed relief. With stroke definitively ruled out, the question was then what had caused symptoms. Different causal explanations were proposed. Many participants adopted a psychological account of their symptoms mentioning stress and exhaustion:

> *"Every day I'm a little bit better, so I think of the reasons I wound up at the hospital in the first place is because I was just exhausted…it has been an on-going thing with me. I tend to overdo it…my mental energy is such that my physical energy hasn't yet sort of caught up with it"* (Participant 8, female, 43)

While reflecting on her admission, another participant also felt her symptoms had started because of a stressful period in her life and she should not have been brought to the hospital at all:

> *"It was just a very stressful time. I wouldn't have gone if they hadn't made me"* (Participant 29, female, 51)

Avoiding making causal attributions seemed to be an active coping strategy. There was a sense that some participants preferred not to ruminate on possible cause:

> *"I'm fine. I don't have any problems. I've had a check-up and they've said that I don't have stroke…It doesn't affect my life because I knew it was not a stroke. Maybe it was just that I was stressed"* (Participant 5, female, 65)

Some participants acknowledged that they had not suffered a stroke but nonetheless gave an opaque neurological account of their symptoms. These accounts were often lacking in detail:

> *"They said they didn't think it was stroke at all, in the end and that it was just factors, factors of stuff going on in my body, like I say, it could be a nervous thing in the body, the nerves in the body that, ehm, are playing up and can give other symptoms"* (Participant 9, male, 67)

Some participants remained uncertain regarding cause two-months later and had no lay understanding of their admission:

> *"They suspected that I had mini stroke, but later, when they discharged me, that's why I'm still confused, they said, 'No, you have not had a mini-stroke'…it seemed to me that they couldn't give me the right information and I was discharged without being, without knowing exactly what happened"* (Participant 14, female, 64)

Participants are most frequently given only a negative diagnosis and told only of the lack of stroke aetiology. The lack of clarity from staff was a direct source of uncertainty for participants, with many noting that staff and by extension, they themselves, do not know what caused their symptoms:

> *"They don't know what happened. They know that it happened but they don't know why"* (Participant 33, female, 51)

> *"There's nothing they can do about it. They said that they can't see any reason for it"* (Participant 22, female, 59)

A sense of frustration due to the lack of a clear explanation from doctors regarding symptom cause was expressed by another participant. This participant was still searching for a positive diagnosis, having had only stroke ruled out:

> *"I didn't get an answer from the stroke ward, except to say, 'We don't think you're having a stroke. We think its migraine related'…I've had all the stroke-like symptoms, eh, but nothing definitive. I don't think there was anything definitive on the scan…but even speaking to my doctors, they've never heard of anyone just losing the use of all their limbs, even temporarily as the result of a migraine…it's like learning to walk again…and I had to fight to get an ambulance to come home because I couldn't walk five paces on my own, you know?"* (Participant 15, female)

One participant described how he feared the lack of a diagnosis meant there may be a more severe underlying cause:

> *"If I experience it again, then I will be back to the doctor. For it to be a reoccurring thing, it's possible that what was going on was stress and I get that but if it reoccurs then, it would be more of a concern for me. And I think, in the back of my mind, when I have, I call it a funny turn, I suppose that's what's going through my mind, is this something like an MS attack? I've got nothing to base it on if I'm being absolutely honest, but I'd be lying if I said it didn't concern me"* (Participant 18, male)

Diagnostic uncertainty also fuelled another participant's anxiety:

> *"I'm very worried about it because I don't know what can happen…I don't know if it will affect me later on or what"* (Participant 10, female)

For other participants, they were more easily able to accept this uncertainty and it did not invoke anxiety or concern:

> *"Occasionally I might feel, if I have a similar symptom like if you close your eyes for a while and open them and the lights goes funny then I think, 'Oh shit, is this happening again?' or something like that, occasionally I get a little bit anxious about it but not really, not to the point where it stops me living my life. Brains are complex things, that's the only thing I'd say"* (Participant 2, male, 23)

One participant, who had had a previous stroke but was admitted with functional overlay, had come to realise that uncertainty was inherent in modern medicine and doctors were fallible, a way of thinking she found useful when she encountered the health care system:

> *"My outpatient appointment was very brief…if I have learned anything from this experience it's that we assume that medicine knows quite a lot, if I can give medicine an identity, because doctors actually don't know and so often times they cannot say what has caused certain things to happen…I just carry on. You know, it's better if you know what's caused it, then you can try to limit it but if you don't know what that's based on, what can I do? There's nothing I can do"* (Participant 23, female, 38)

This participant had a history of CFS so it is possible that her ability to cope with uncertainty within the medical system was more developed than others as a result of her experience with the diagnosis.

Other participants coped with the uncertainty, incorporating it into their understanding of their symptoms:

> *"It wasn't under my control, it was absolutely something I couldn't control myself, but when it finished, it finished and perhaps it is coming back, I don't know…the consultant that explained everything, he couldn't say what happened to me and he just said, 'I don't know what happened to you. No one knows what happened to you. What happened is finished and now you are ok' and I thought, 'Okay'"* (Participant 27, female, 58)

In summary, two months after discharge from the HASU, equal proportions of participants have seen their symptoms abate or continue. Consistent across most participants however was the sense that they left the hospital ward with little understanding of why their symptoms had

occurred in the first place. Some participants seem to accept this uncertainty, but for others, the lack of understanding is problematic and remained a source of anxiety.

4.4 Discussion

4.4.1 Main findings

4.4.1.1 Questionnaire findings

Results from the Brief-IPQ indicate that while admitted to the stroke ward, participants believe their symptoms severely affect their life; they have little control over these symptoms; they are concerned about their symptoms; and these symptoms have a high negative emotional impact on their life. Participants believe that the treatment they receive on the ward will help improve their symptoms. On average, they are neutral in their response to questions related to the extent of their understanding of symptoms, how long they think symptoms will continue and how much it will affect their life.

The mean emotional response score (*How much do your symptoms affect you emotionally? e.g. feeling angry, scared, upset or depressed*) reported by functional stroke participants was high and similar to responses from patients with type two diabetes (Vedhara et al., 2012), bipolar disorder (Lobban et al., 2013) and women with depression (Brown et al., 2010). Functional stroke patients reported a strong belief in the consequences of their symptoms (*How much do your symptoms affect your life?*) similar to responses reported in patients with breast cancer (Kaptein et al., 2013), lung cancer (Kaptein et al., 2011) and patients with depression in advanced disease stage palliative care (Price et al.). Functional stroke patients report that they had little personal control over their symptoms with a mean 'personal control' score on par with patients with ankylosing spondylitis (Hyphantis et al., 2013) and type two diabetes (Bean et al., 2007). The baseline questionnaire results suggest that functional stroke patients have strong negative emotional responses to a HASU admission and feel a lack of control over their symptoms, similar to the experiences of patients with serious physical maladies.

Two months later, there is an improvement in some symptom perceptions. Patients' view of the consequences of their symptoms, the extent that they experience symptoms, their concern about the symptoms and their emotional response all significantly improved with time. There was, however, no significant improvement in the length of time patients believed their symptoms would continue, the amount of personal control they felt they had over their symptoms or their understanding of their symptoms. Patients were hopeful that treatment would benefit their symptoms at both baseline and follow-up.

Patients with strong illness identities, who predict long illness timelines and severe consequences have higher future healthcare use, independent of doctors' ratings of illness severity (Frostholm et al., 2005). In a prospective study of CFS, the strength of patients' belief in a somatic cause for their symptoms predicted poorer symptom outcomes (Wilson et al., 1994). The finding here that some perceptions improve over time with no psychosocial intervention is encouraging, particularly as previous research is mixed on the ability of psychosocial interventions to improve illness perceptions. Some psychosocial interventions intended to improve illness perceptions in physical disease found no change for instance (Skovbjerg et al., 2012; Welschen et al., 2012).

While some aspects of patients' illness perceptions may improve on their own, an intervention addressing patients' perception of personal control over their symptoms and their understanding of the nature of functional symptoms might be fruitful for future research. Examples of interventions which have improved patients' sense of personal control include a psychological, family-based intervention with motivational interviewing methods for type two diabetes patients (Keogh et al., 2011), a cognitive behavioural intervention for cardiac outpatients (Jonsbu et al., 2013) and an 18-week text-messaging programme for patients with asthma (Petrie et al., 2012).

These interventions were designed to improve the outcomes of patients with physical health disorders. While one study testing an online psycho-education programme reported improvements in personal control perceptions of bipolar disorder patients (Proudfoot et al., 2012) an intervention designed specifically to improve the symptom perceptions of FND patients would be worthwhile.

4.4.1.2 Qualitative findings

Results from qualitative findings were classified into three thematic families, namely 'phenomenological experiences', 'symptom attributions', and 'views on the future'. 'Phenomenological experiences' were classified into four sub-themes, including patients' experience of their symptom onset, their help-seeking behaviour prior to admission, their experiences as inpatients and their emotional responses to admission. The 'symptom attributions' theme was further classified into three sub-themes including patients' common attributions, locus of control and authenticity. 'Views on the future' were further sub-divided into views on recovery, research and an ideal treatment. Two-month follow up interviews were thematically categorised according to 'symptom experiences' and 'symptom attributions'.

Some patients gave a detailed, thorough narrative of the onset of their symptoms and their arrival to hospital. Symptoms were an interruption to the normal course of their day. For participants with more insidious symptom onsets, many described out-of-body experiences and dissociative states, similar to symptom onset experienced by patients with functional weakness (Stone et al., 2012). Previous literature regarding patients with unexplained or functional symptoms suggests patients' illness narratives are often chaotic with no clear beginning or end (Frank, 1995). In our study however, participants were consistently coherent in their descriptions of symptom onset. Previous research on illness narratives with patients with unexplained symptoms was often conducted in general practice where symptoms are more likely to be established and chronic. In this sample, perhaps because symptom onset was recent, patients' demonstrated clarity in their recall and narration of events.

Some participants described a phenomenon where, when seeking help, their symptoms often got worse. Salmon (2006) suggested that patients' presentations might intensify if they sense a doctor's reluctance to engage or to accept their symptoms at face value. Salmon argues that as doctors propose physical investigations and treatments in response to the escalating severity of functional symptoms, they can inadvertently induce and entrench somatisation. It may also be possible that the act of describing symptoms could worsen symptoms as patients are forced to focus on symptoms themselves, something that may intensify the symptom experience (Barsky et al., 1993). It is not possible to draw causal conclusions here, but it may also be the case that as medical care escalates, participants' anxiety or panic increases and symptoms worsen. The escalation of care may also re-inforce participants' pre-existing beliefs about the seriousness and potential somatic nature of their condition.

Our qualitative findings regarding patients' emotional responses mirror results from the Brief-IPQ. Functional stroke patients describe an array of strong negative emotions in response to their HASU admission from feelings of depression, distress, anger, disappointment, as well as stoic resignation. Regarding stoicism, the minimisation of emotion has previously been reported in research with patients with FMD (Epstein et al., 2016). Participants in our study expressed apprehension that they might not find a potential cause for their symptoms, a reality that often remained two months later.

Our findings somewhat contradict previous research suggesting that somatoform disorder patients have lower levels of emotional awareness (Subic-Wrana et al., 2005). The stoic response was in itself an acknowledgement of a potentially strong emotional reaction. A study of patients with medically unexplained symptoms in general practice found these patients were more likely to look for emotional support than patients with symptoms that had a physical explanation (Salmon et al., 2005), contradicting the common view that patients with

unexplained symptoms deny their psychological needs. Stoicism, or at least professed stoicism, was common in our study however and this seemed to be a response to the strongly negative emotional experience of being admitted to the ward.

Causal beliefs, uncertainty, control and coping styles were common inter-related themes throughout our interviews. Most participants were uncertain about the potential cause of their admission with many mentioning anxiety, psychological factors, and stroke itself. The uncertainty that emerged may be partly due to the context of the interviews – participants may have preferred to wait until they were discharged or to talk to their GP before deciding conclusively what they believed caused their illness. This is unlikely to have played a prominent role however as participants' uncertainty remained in the two-month follow-up interviews.

It is most likely that the lack of certainty reflects the lack of diagnostic information participants received from clinical staff. Clinical stroke staff appeared to adopt a dichotomised view of patients as stroke sufferers or non-stroke patients and non-stroke patients with potential functional aetiologies received little to no explanation from staff. Previous research suggests diagnostic uncertainty can lead to high emotional distress, anxiety and depression (Mischel et al., 1991; White & Frasure-Smith, 1995) and in our study, this lack of certainty may partly explain patients' negative emotional responses.

Not all participants were uncertain about the cause of their symptoms; some held psychosocial explanations. This contradicts Rief et al.'s (2004) primary care study where somatoform patients held exclusively physical attributions. It is possible that patients with unexplained symptoms seen in primary care have more chronic symptoms and as a result of the length of symptom experience, may be less open to psychosocial accounts. Our results corresponds with findings from a study of patients with somatoform disorders in an allergy clinic who also recognised the role of psychosocial factors (Groben & Hausteiner, 2011). Our results suggest that illness attributions may be multifactorial in nature and while some patients might be uncertain, others are open and receptive to psychosocial accounts.

Illness beliefs affect the long term outcome of patients with both physical and mental health issues, for example patients who did not know that they were hypertensive showed a threefold increase in the days of work missed after they received a diagnosis (Haynes et al., 1978). More research is needed to tease apart the causal explanations that patients with unexplained symptoms in stroke settings develop. In our study it was often unclear whether participants believe psychosocial factors modify, mediate or directly cause physical susceptibility to a somatic event or whether they believe their somatic symptoms can be entirely explained by psychosocial factors.

Patients almost unanimously described experiencing little to no control over their symptoms, but many felt hopeful that they could control their recovery. These findings correspond with results from the Brief-IPQ where patients report low rates of personal control over symptoms. It is likely that a lack of perception of symptom control is linked to the uncertainty inherent in many patients' symptom attributions. Individuals who perceive symptoms as beyond their control, have poorer health outcomes, poorer quality of life (Brown et al., 2015), report more somatic symptoms and higher rates of neuroticism and anxiety than patients with internal locus of control styles (Hoehn-Saric & McLeod, 1985). It is possible that learned helplessness arises when patients feel they lack control. A longer follow-up period and the inclusion of measures like the Generalised Self-Efficacy scale (Schwarzer & Jerusalem, 1995) and the Multidimensional Health Locus of Control scale (Wallston et al., 1978) might help account for such factors in future studies.

Throughout interviews, participants expressed concern that they might not be taken seriously by stroke clinicians. They were often acutely sensitive to perceived negative inferences made about them by clinical teams. This is a feature of much of the qualitative literature on patients with contested diagnoses like unexplained physical symptoms (Nettleton et al., 2005; Peters et al., 2008; Salmon et al., 1999; Stone, 2014), chronic pain (Osborn & Smith, 1998), CFS (Clarke, 2000) and fibromyalgia (Cunningham & Jillings, 2006; Sturge-Jacobs, 2002). These papers highlight how individuals' lack of outward signs of illness or disability can arouse suspicion in others causing patients' credibility to be questioned. Results from our study depart from these findings somewhat. Illegitimacy is experienced only in relation to staff members. Patients have short, acute symptoms which have often not yet become chronic. Patients describe having their legitimacy as patients questioned by doctors but do not mention their wider social circle of friends or family. Instead, friends and family appear supportive in response to symptom onset, often seeking medical care and visiting the patient on the ward.

The findings from clinicians' interviews in Chapter Three suggest that patients' concerns about being viewed as legitimate recipients of care may not be entirely unwarranted. The results of our study suggest that patients are not immune to the views of their clinicians and these results reinforce the need for clinicians to avoid making moral judgements at the patient's bedside (Raine, 2004).

Two months after their discharge, some participants continued to experience symptoms while some had had a complete remission. This was reflected in the Brief-IPQ results where there was a significant drop in participants who described experiencing many severe symptoms. Those who recovered completely tended to have made lifestyle changes and described improvements in their fitness and mood. In a three year follow-up study of functional motor

disorder patients in a tertiary referral clinic, 9.5% had a complete abatement of symptoms, 33.3% of participants improved but 57.2% of patients' symptoms were the same or worse (Feinstein et al., 2001). In our study, a higher proportion of patients improved (44%) and a lower proportion worsened (40%), at least in the short-term. Our follow-up period of only two-months however may not capture the true chronicity of these symptoms.

Symptom attributions changed to some degree two months after their discharge but most participants were still unsure of the cause. There is conflicting evidence on whether or not receiving a diagnosis or label is helpful in the treatment of functional symptoms. Huibers and Wessely (2006) have argued that being labelled with a functional diagnosis can lead to the reinforcement of illness beliefs and an acceptance of a fully-fledged sick role and the appropriation of a disease identity. The alternative argument is that receiving a label can be an empowering act, removing uncertainty and bringing relief and legitimacy. Patients with CFS, for instance have described receiving a diagnosis as the most helpful event in the course of their illness (Woodward et al., 1995). In our study, functional patients admitted to HASUs should, at the very least, receive a concise, honest explanation of the nature of functional symptoms, and if symptoms persist and become chronic, they should receive a prompt diagnosis that might help patients access future effective treatment.

4.4.2 Strengths and limitations

This study is the first to assess the experiences of patients with unexplained or functional symptoms admitted to a hyper acute stroke ward. The study period of ten months and the broad inclusion criteria allowed for the recruitment of a representative sample of participants. The use of the Brief-IPQ during the semi-structured interview was an attempt to achieve data triangulation, allowing for some cross-verification of our results.

Results in this study correspond with results in Chapter Three. In Chapter Three, clinicians described how they avoided giving positive diagnoses or terms that might label participants and deliberately relied on obscure labels when discussing diagnosis. Results from the current study suggest that the resulting diagnostic uncertainty has negative psychological effects on patients who expect the normal process of diagnosis, treatment and referral to operate. This uncertainty persists two months after discharge.

Participants interviewed in this study were only those admitted to the HASU, most commonly after assessment by a paramedic and a doctor in the Accident and Emergency department. These patients will be, at least symptomatically, different to functional disorder patients seen by a paramedic or A&E doctor but not admitted to the HASU. Their physical symptoms may look more convincing and they may present with a less obvious psychological indication than

patients who are not subsequently admitted. It may not be possible therefore to generalise the results of our study to functional disorder patients not admitted to acute settings.

Related to this issue is the fact that interviews took place at one HASU site in a single NHS Trust. Further research is required to ascertain whether our results are generalisable to other HASU wards or acute care settings. Unexplained symptoms are common in nearly every medical setting (Reid et al., 2001a) but more research is needed on the specific experiences and processes related to patients' admission to acute settings generally as these may differ to patients' experiences in primary care or on non-acute wards.

The transience of some patients' symptoms is worth noting. Not all participants in this study would qualify for a diagnosis of functional neurological symptom disorder, or indeed any mental health diagnosis. Some participants experienced stoke along with functional overlay. Patients often experienced acute symptoms which resolved while on the stroke ward and which did not return. Others described what were likely to be chronic symptoms that would not meet the diagnostic threshold. This might be problematic in an epidemiological study measuring incidence but our study aimed to understand experiences, and the presence of unexplained symptoms. The finding that symptoms were often transient and sub-diagnostic is an important finding in itself with implications for future interventions in this area.

Participants had a wide range of unexplained symptoms, some had previously experienced stroke in the months prior to their admission and some had had a stroke admission. The heterogeneity of symptoms has implications for the interpretation of the Brief-IPQ results. A larger sample size would have allowed for symptom type and length of symptom experience to be accounted for in the analysis of the questionnaire. Future research in this area would benefit from adopting a multi-site recruitment approach to increase the sample size.

The researcher was embedded on the ward and in some cases participants sought reassurance and advice during the interview. As the researcher, I wished to remain impartial throughout the interviews although in some cases it was difficult to maintain this in the face of some patients' clear distress. In some instances, it was necessary to speak to the ward's clinical neuropsychologist after the interview to let them know the patient was experiencing difficulties.

At the two-month follow-up, not every participant responded to the request for an interview. It is possible that non-responders were different to responders, they may have had worse outcomes or it is possible their symptoms completely resolved. Despite this, the follow-up rate in this study was relatively high at 83% so response bias is not a huge concern in this study.

Our follow-up interviews were conducted via Skype, but without video. While internet based methods of interviewing are increasingly common due to their efficiency and affordability, it was harder to establish rapport with participants during the follow-up interviews. As a result, some of the richness of the interaction may have been lost. This may be reflected in the fact that Skype interviews took less time than our face-to-face baseline interviews. However, using Skype allowed participants to be interviewed in their own home, at a time that suited them, with little interruption to their day and likely contributed to the high response rate.

4.4.3 Conclusions

Patients with functional stroke symptoms who are admitted to stroke settings have a strong negative emotional response to their admission. While inpatients, many believe they have had a serious cerebrovascular event and that there will be serious negative consequences in the future. Most do not feel they have any personal control over their symptoms. Two-months after their discharge from hospital participants continue to believe they have no personal control over their symptoms, have little understanding of the symptoms which brought them to the ward, and are uncertain as to the symptom cause. Most continue to feel they did not receive an adequate explanation from clinical staff.

Patients might benefit from improved doctor communication through the use of well-developed explanation and positive diagnoses but patients with higher rates of depression and anxiety might also benefit from interventions targeting perceptions of personal control and emotional responses.

Chapter Five: A case-control study of 322 functional motor disorder patients in SLaM

5.1 Introduction

Functional motor disorders comprise symptoms such as weakness, numbness, tremor, gait disorders and paralysis which are not caused by neurological disease. Patients can present with abnormal motor symptoms which are incongruous with the motor disorders that occur in neurological disease.

The previous three chapters outlined research examining functional neurological symptoms and their occurrence within stroke settings and the perspectives of patients and clinicians. This study and the proceeding chapter examine the occurrence of FMD symptoms in one large mental health trust.

It is worth noting that the definition of FMD used in this and the subsequent chapter relates to functional motor disorder that includes, but is not restricted to functional movement disorders. Functional motor disorder is a broad category that in our chapters relates to abnormal movements like gait disorders and tremor but also includes weakness and any symptoms affecting motor faculties like speech, swallowing, visual, or urinary disturbances.

This introduction outlines the epidemiology, clinical features, physical health comorbidities, life events, treatment, and prognosis of FMD before outlining our study's aims. Evidence is drawn from functional disorders generally, and where possible, from evidence on FMD patients specifically.

5.1.1 Prevalence

As outlined in the introduction to this thesis, the frequency of FND varies depending on the setting, the case definitions employed and the methods used to ascertain cases.

Epidemiological studies of FMD specifically are rare. Information on their prevalence comes from movement disorder and general neurology clinics. In movement disorder clinics in the US a rate of 3% has been reported (Factor et al., 1995; Thomas & Jankovic, 2004) but anecdotally it has been reported to be as high as 20% (Hallett, 2006). In a general medical setting, Portera-Cailliau et al. (2006) reported a rate of 10%, and in general neurology clinics there are reports of rates between 1-9% (Lempert et al., 1990; Marsden, 1986).

The differences in rates could reflect local referral patterns and clinicians' specialities, clinic types, the diagnostic criteria and methods used to assess patients, and clinicians' awareness of functional symptoms. A robust epidemiology of functional disorders has suffered due to the lack of consensus on diagnostic criteria and continual changes to its definition.

5.1.2 Socio-demographics

FMD patients have a socio-demographic profile that matches most other functional disorders. In Factor's (1995) study of functional movement disorders, 61% of patients were women and most were young to middle-aged. Hinson and Haren (2006) reported a mean age of onset between 37-50 years but FMD may also affect children and the elderly. Batla et al.'s (2013) retrospective study of patients with functional movement disorders reported 21% of patients' symptoms began after the age of 60 while Schwingenschuh et al. (2008) reported a mean age of onset in children of 12.3 years of age. In children with functional movement disorders, dystonia, tremor, and gait disorders were the most common symptoms.

5.1.3 Clinical features

Patients with FMD present with a range of symptoms. Symptoms can begin suddenly and without warning and unlike organic movement disorders, their progression is often fast (Williams et al., 1995). The phenomenology of the disorder can shift over time and symptoms can change form and type.

Tremor is frequently reported as the most common type of functional movement disorder seen in movement clinics (Factor et al., 1995; Hinson & Haren, 2006). One such clinic in Toronto reported that tremor was the most common functional symptom, comprising 32.8% of presentations, followed by dystonia (25%) (Miyasaki et al., 2003). Batla et al. (2013) also found tremor was the most frequent symptom while a further study reported dystonia as the most common symptom, followed by tremor (Fahn & Williams, 1988). These symptom frequencies should be interpreted with caution given the possibility of referral bias affecting the type of patients seen in differing services.

The following section outlines existing evidence on the individual features of specific motor symptoms.

5.1.3.1 Tremor

Functional tremor is often marked by its sudden onset, variability in severity, and variability in the part of the body affected. It commonly affects the arms but can reach all parts of the body including hands, legs, and head (Schwingenschuh & Deuschl, 2016). Maximum disability has been said to occur directly after onset and symptoms can follow a static or fluctuating course (Kim et al. 1999). It is often distinguished from organic disease as it can change or stop depending on the level of attention paid by the patient to the affected limb (van Poppelen et al., 2011). Distraction techniques are often employed by clinicians such as asking patients to tap the unaffected limb at a different pace to the tremor (Kenney et al., 2007).

Schwingenschuh et al. (2011) found no single test could adequately distinguish functional tremor from organic tremor seen in Parkinson's disease, but employing a combination of electrophysiological tests has good sensitivity and specificity (Hallett, 2010).

Functional tremor affects more women than men with rates of female morbidity ranging between 70 - 80% with a mean age of between 42 and 44 years (Deuschl et al., 1998; Jankovic et al., 2006). Jankovic et al.'s (2006) study reported that 24% of functional tremor patients had a psychiatric illness before their symptom onset and over half experienced comorbid somatic symptoms like pain.

Patients have a poor prognosis; Janokovic (2006) reported that 85% of patients retired after the onset of their tremor, subsequently retired and McKeon et al. (2009) found that 64% of patients continued to experience moderate to severe symptoms after five years.

5.1.3.2 Gait disturbance

Normal gait is defined by two principles; equilibrium and locomotion. Equilibrium is the ability to assume and maintain an upright posture of the head and trunk, while locomotion is the body's ability to propel itself forward (Nutt et al., 1993). This is disrupted in gait disorders. Gait disorders often occur due to arthritis or neurodegenerative disease. Functional gait disorder patients have no positive pathology or known pathogenesis. In general medical settings, functional gait disorders have been reported between 9-10% (Miyasaki et al., 2003; Stolze et al., 2005).

Patients with abnormal functional gait disturbance can show an excessive slowing of movement and buckling of the knee (Baik & Lang, 2007). Symptoms may include veering from side to side when walking, limping on one leg, walking hesitantly as if on ice, and swaying erratically in the upper body (Jordbru et al., 2012). Other movement patterns include tightrope walking, trembling walking, truncal jerking, and astasia-abasia, the inability to stand upright unassisted (Sokol & Espay, 2016). Falls and injury as a result of the disorder are reported to be rare (Jankovic, 2015).

Other clinical signs have gained some attention such as 'huffing and puffing', grunting, grimacing, and breath-holding while moving. These have been described in 44% of patients with functional gait disorder (Laub et al., 2015), and are explained as the excessive demonstration of effort for the benefit of the clinician. Park et al. (2015) proposed 'the whack-a-mole' sign where the suppression of movement in one body part is followed by the re-emergence of the movement in another area. This was tested in a movement disorders clinic and was found to have low sensitivity (28%) but high specificity (91%).

It can be difficult for clinicians to distinguish functional gait disorders from organic disease but Fung (2016) argued that if a single symptom is difficult to define, the combination of a patient's clinical syndrome (for instance multiple medically unexplained symptoms) as well as inconsistencies in their presentation makes an organic diagnosis unlikely.

5.1.3.3 Weakness

Paralysis is a classic functional symptom. Functional weakness can occur in many manifestations such as paraparesis, hemiparesis, triparesis, etc., and complete paralysis (Lanska, 2006). Of new neurology outpatients, 1.5% had functional weakness (Stone et al., 2009b), similar to the 2% rate from neurology inpatients (Parry et al., 2006). Functional paralysis in neurology inpatients may range between 1-18% (Metcalfe et al., 1988; Schiffer, 1983) .

A study by Stone et al. (2010b) reported hemiparesis was the most common type of functional weakness in a study of functionally weak patients referred to consultant neurologists, the leg was involved in 94% of cases. Symptoms lasted a mean of nine months, 79% of patients were women, and their mean age was 39 years. Comorbid symptoms included fatigue, pain, gastrointestinal symptoms, tremor, and NES. Patients had a higher frequency of psychiatric disorder such as depression and panic compared to controls with organic weakness and higher use of walking aids such as wheelchairs, bath chairs, Zimmer frames and stair lifts. Functional weakness patients were more likely to give up work as a result of illness than controls but both groups were as likely to receive disability benefits.

Like tremor, weakness can have a sudden onset and has been likened to the onset of stroke. It can be accompanied by panic and dissociation and may begin after an injury to the affected limb (Stone et al., 2012b). Crimlisk et al. (1998) found 42% of FMD patients had a history of neurological disease.

Common signs in the presentation include 'la belle indifference' although, as previously noted, its utility and validity has been questioned; 'Hoover's sign', an involuntary extension of a weak leg when the healthy leg is forced to extend against resistance (Hoover, 1908); a dragging monoplegic gait, where one leg is dragged with the knee extended and hip rotated; and collapsing weakness. Stone et al. (2010) have discussed the possibility that patients have reduced ticklishness and can present with 'arm protection' where patients protect their arm in a flexed position in the absence of pain by laying it across their lap or holding it in a flexed position when walking. Other tests for upper limb weakness include 'drift without pronation' (Daum & Aybek, 2013). Patients are asked to keep their arms outstretched and to hold the position with their eyes closed for as long as possible. A positive functional sign is a downward

drift of the arm without pronation. The 'double crossed arm pull' test is a sign for functional monoparesis (Biller et al., 2011). The patient's wrists are grabbed when crossed across their chest. When asked to pull back as hard as possible the patient may pull both arms back.

There are a large number of such tests and it has been advised that the purpose of the tests is shared with patients during clinical encounters to form part of their physical and psychological rehabilitation (Stone & Aybek, 2016).

5.1.3.4 Sensory symptoms

Functional sensory disturbance can affect any part of the body. Symptoms often include feeling that a limb is not part of the body; altered sensations on one side of the body or on the face, arm or leg; or fleeting bodily sensations such as buzzing sensations. Patients may present with a disturbance of pain sensation and reductions in the perception of touch and temperature. Some presentations can be extreme where a patient loses the sensation of an entire arm or leg (Stone & Vermeulen, 2016). Sensory disturbances often co-occur with functional weakness (Stone et al., 2002). Stone and Vermeulen (2016) note that impairment is often short in duration and commonly affects only half the body.

Toth et al. (2003) reported that 74% of patients with hemisensory syndrome were female with a mean age of 35. In a cohort study by Stone et al. (2003), 60 patients with functional or sensory disturbance (it is unclear what proportion had only sensory symptoms) reported their symptoms continued for a median duration of 12.5 years. Where a whole limb is affected, studies have found the sensory disturbance is often demarcated along clear boundaries, most commonly the shoulder and the groin (Janet, 1907). Stone and Vermeulen (2016) describe a splitting where patients can feel they are 'cut in half' or 'split down the middle'. In a study of 405 patients with functional symptoms, the most common sensory symptoms were hypo- or anaesthesia followed by dysesthesia (Lempert et al., 1990). Numbness is said to more frequently affect the trunk than arms or legs and the disturbed sensation can flip from one side to the other (Stone & Vermeulen, 2016).

One clinical sign of sensory loss is the 'splitting of vibration sense'. Vibration is perceived mostly through bone conduction. By placing a tuning fork on the right or left of the forehead, the sensation should be felt identically on either side as the same bone is involved. This test's sensitivity has been reported to be 95% in 19 patients with functional symptoms however it has poorer specificity (Rolak, 1988).

5.1.3.5 Other symptoms

This section outlines the less common functional motor symptoms of speech, facial, and urinary disturbance.

Functional speech disorders cover a range of abnormal speech patterns that cannot be accounted for by organic disease. These disorders often co-occur with other functional symptoms. “Hysterical mutism” was described by Charcot as “sudden onset, impossibility of speaking or crying out [but the] perfect preservation of intelligence”. Baizabal-Carvallo and Jankovic (2015) reported the most common functional speech disorder seen at the Mayo clinic over ten years was stuttering-like dysfluency followed by articulation deficits. Women accounted for 76.6% of these patients. Speech and language therapies show positive results. Duffy (2016) notes that when treating functional speech impairment with speech therapy, patients should be helped to develop an explanation they can provide to others about the nature of their symptoms.

Functional facial movements can affect the eyelids, tongue, and muscles of the face. Uncontrollable and painful contractions of the eye can account for up to 7% of FMDs (Factor et al., 1995). Symptoms can be episodic in onset and inconsistent in their presentation and again, more commonly affect women and have been associated with migraine and facial weakness (Fasano et al., 2012). These authors also reported that symptoms most frequently affect lips, eyelids and nasal regions. Little is known about the treatment of the disorder but in Fasano et al.’s (2012) study, 21% of patients spontaneously recovered.

Urinary dysfunction is another type of functional symptom and can present in a variety of ways. Functional urinary retention was described by Charcot as “hysterical ischuria” (Charcot, 1877). This has been reported in young women and has been linked to urinary tract infections and early emotional deprivation (Wahl & Golden, 1963). In a retrospective review of patients with functional movement disorder, Batla et al. (2016) found 20% of patients had lower urinary tract dysfunction. Of these patients, overactive bladder symptoms were the most frequent and patients with fixed dystonia were most commonly affected.

Other types of FMDs include jerking movement, tics, eye movements, swallowing difficulties, and some speech and voice disorders. Functional symptoms can affect a wide range of motor functions and they can be debilitating and disturbing. The following sections outline life experiences, diagnosis, treatment and prognosis of FND.

5.1.4 Life events

Functional disorders have been historically associated with traumatic life events or psychological stress. Up until recently, the identification of a psychological antecedent was a diagnostic criterion of functional disorder. This is no longer the case, but theories of functional disorders frequently link their development to psychosocial precipitants. Research in this area tends to classify life events into those occurring in childhood that relate to sexual, physical and emotional abuse, often classed as trauma, and events occurring in adulthood, precipitants occurring closer to the time of symptom onset.

Sexual abuse is frequently described in FND presentations. Much of the research in this area focuses on NES. Of research that does not focus on NES alone, the rates of abuse vary. Roelofs et al., (2002) reported that in FND patients there was a 28% rate of physical abuse; a 24% rate of sexual abuse; a larger array of types of physical abuse; sexual abuse of a longer duration; and more frequent incestuous experiences compared to patients with affective disorders. Sar et al., (2004) reported a rate of childhood sexual abuse (CSA) of 26.3%, emotional abuse of 34.2%, a physical abuse rate of 44.7%, and an overall neglect in childhood rate of 57.9%. In patients with medically unexplained gastrointestinal problems, 13% experienced physical abuse and 13% experienced sexual abuse (Reilly et al., 1999). In patients with functional voice disorder, 41% experienced physical abuse and 32% experienced sexual abuse (Baker et al., 2013).

A systematic review reported an average CSA rate of 33.2% in NES patients (Sharpe & Faye, 2006). The incidence of CSA in functional motor disorder may be lower than NES patients with previous reports ranging from 3-12.5% (Binzer & Eisemann, 1998; Stone et al., 2004b; Voon et al., 2010). These studies recruited from neurology settings where the abuse incidence may be lower than that seen in psychiatry patients. Nicholson et al. (2016) reported a life time sexual abuse rate in FMD of 41.9%, while McCormack et al. (2013) reported a CSA rate of 36.4%. Life time experience of abuse will be higher than abuse experienced in childhood alone and both studies' recruited from specialist tertiary services where patients may have more severe symptoms and more traumatic experiences.

Life events, as distinct from childhood sexual and physical abuse, have also been explored in relation to the development of FND. Binzer et al. (2004) found no differences in the number of life events three months prior to symptom onset between NES and epileptic patients. Testa et al. (2012) found NES patients did not experience a higher frequency or severity of life events, but rated them as more distressing. Research specifically excluding NES patients found FND patients reported more recent life events compared to healthy controls (Steffen et al., 2015).

Roelofs et al. (2005) reported a link between childhood trauma and functional neurological symptoms but found that this was mediated by the occurrence of recent stressful life events. In their study, life events were most commonly related to work and relationships. A study by Kozlowska et al. (2011) found 27% of conversion patients had experienced recent bereavement.

Patients frequently experience physical precipitating factors with rates varying from 24-100% (Baik & Lang, 2007; Fasano et al., 2012; Jankovic et al., 2006; McKeon et al., 2009; Ranawaya et al., 1990; Schrag et al., 2004; Stamelou et al., 2012). Common types of physical precipitants include injuries in work, back and neck injuries, surgery, motor vehicle accidents, and head injuries. A systematic review reported that 37% of patients had a physical injury prior to symptom onset (Stone et al., 2009a). A retrospective review of 151 patients with functional movement disorders found the most common type of precipitating events were physical trauma, followed by 'emotional life events' (Batla et al., 2013). Physical injury or trauma was as high as 80% in functional patients in a movement disorders clinic (Pareés et al., 2014), while a retrospective study from seven tertiary movement disorder clinics described stress as the most common precipitating factor (61%), followed by physical trauma (14.8%) (Fasano et al., 2012). In a study of functional tremor, half of participants with acute symptom onset mentioned a precipitant which included a medical procedure, an upper respiratory tract infection, and work-related pain (McKeon et al., 2009). Physical trauma and organic disease are therefore not uncommon experiences prior to a functional symptom onset.

While the literature suggests that a substantial proportion of FND patients have experienced adverse life events, a proportion have not. The methods used to assess these life events and the position of the person will likely affect the rate itself and it is possible that under-reporting is common throughout.

5.1.5 Diagnosis

The diagnosis of individual functional symptoms and the use of positive physical signs have been mentioned in previous sections. In the diagnosis of FND generally, a thorough history and clinical examination is important and will often necessitate the use of special investigations.

Three clinical criteria, developed to help formalise and assist the diagnosis. The Fahn-Williams criteria (Williams et al., 1995) are the most widely used. These categorise diagnostic certainty as: i) documented, ii) clinically established, iii) probable, and iv) possible. The Shill-Gerber criteria (Shill & Gerber, 2006) rely on clinical elements that suggest inconsistency with an organic disorder such as disproportionate pain or fatigue, and secondary gain. However, the

Fahn-Williams and Shill-Gerber criteria show poor inter-rater reliability when assessing cases with a high degree of uncertainty (Morgante et al., 2012).

Improvements in the Fahn-Williams criteria have been proposed (Gupta & Lang, 2009). These authors argue that the 'possible' category should be removed and the diagnosis of FMD should be made on the basis of positive findings. In the case of functional tremor, for example, positive signs like lack of family history, sudden onset, spontaneous remission, shorter duration of tremor, suggestibility and distractibility could help inform the diagnosis (Kenney et al., 2007).

There has been a drive in recent years to develop criteria which are based on positive signs in order to improve the reliability and validity of diagnosis. Such a task is not straightforward as any such criteria have to account for the possibility that patients may have both a functional and organic disorder.

5.1.6 Prognosis

The prognosis for FMD patients is relatively poor. A systematic review with a mean follow-up time of 7.4 years found 40% of patients were the same or worse at follow-up and for patients whose symptoms had resolved, many did not experience complete symptom remission (Gelauff et al., 2014). Anderson et al. (2007) found increased psychiatric morbidity, and similar levels of disability and quality of life when they compared functional motor and Parkinson's disease patients, despite functional patients being younger, with a shorter disease duration.

A range of clinical factors have been linked to patients' long-term outcome. Factors associated with poorer outcomes in patients with functional movement disorder include a longer duration of symptoms, an insidious onset of symptoms, the presence of an Axis-1 psychiatric diagnosis (Binzer & Kullgren, 1998; Feinstein et al., 2001), higher age at symptom onset (Stone et al., 2003), and receipt of financial benefits (Crimlisk et al., 1998; Mace & Trimble, 1996). Improved outcomes have been linked to being female (Czarnecki et al., 2012), and a change in marital status during the follow-up period (Crimlisk et al., 1998).

Gelauff et al.'s (2014) review indicates that there may be differences in patients' outcomes depending on the functional motor symptom type. Patients with functional tremor generally had poor outcomes with 44-90% of patients remaining the same or worse at follow-up (Jankovic et al. 2006; McKeon et al., 2009). The prognosis of patients with weakness and paralysis appears to be better. Stone et al. (2003) found patients with only sensory symptoms at presentation had higher physical and social functioning, and reduced pain at follow-up compared to patients with sensory symptoms as well as weakness. The same authors note

cautiously that patients with sensory symptoms alone have a relatively good prognosis compared to those with a broader range of functional symptoms (Gelauff & Stone, 2016).

5.1.7 Aim of study

Current research on functional motor disorder is characterised by low sample sizes and case studies (Binzer et al. 1997). Control groups, if used at all, are often comprised of neurology or brain injury patients. This may lead to overestimates in the assessment of the risk of psychiatric comorbidities and underestimates in the risk of physical comorbidities. Functional disorder patents are often seen in physical health settings and, following the application of tests and clinical examinations, they are frequently discharged. A number will be referred for a psychiatric or psychological consultation but the demographic, social and clinical profile of these patients is poorly understood. Most research in this area comes from liaison psychiatry in general medical settings and little from psychological and psychiatric services.

This study aimed to establish a cohort of patients with FMD in order to investigate patients' socio-demographic and health factors, life experiences, and clinical outcomes. The characteristics of this patient group were compared to a random sample of psychiatric patients derived from the same database to allow for the identification of specific risk factors in FMD presentations.

5.2 Methods

5.2.1 Study setting

Data from this study were collected from the Clinical Record Interactive Search (CRIS) (Stewart et al., 2009).

CRIS is a case register which provides de-identified information from electronic clinical records from secondary and tertiary mental health services provided by SLaM NHS Trust. The Trust provides mental health care in the London boroughs of Lambeth, Southwark, Lewisham and Croydon. Electronic clinical records have been used by the Trust since 2006 in the form of the electronic Patient Journey System (ePJS). This is a single system where daily activities, medication, diagnoses, correspondence, health scores and all patient information is recorded. CRIS was established in 2008 to allow the search and retrieval of de-identified ePJS information for research purposes. In 2016, it held records for over 250,000 patients (Perera et al., 2016).

5.2.2 Data collection

5.2.2.1 Inclusion criteria

Inclusion criteria for cases in this study included:

I. Patients who received a primary or secondary ICD-10 diagnosis of 'Conversion disorder with motor symptom or deficit' (F44.4); or
II. Participants with any F44 diagnosis and evidence of FMD symptoms; or
III. Any patient with confirmed functional motor disorder symptoms but no ICD-10 diagnosis marked in structured text; and included
IV. Only patients aged over-18.

For each potential patient, evidence was sought that their symptoms could not be entirely explained by a physical disorder (e.g. neurologists' letters confirming a functional explanation for symptoms). If there was no sound evidence of a confirmed functional motor disorder, or if the clinician was not certain that symptoms could be explained by a functional neurological diagnosis, patients were excluded. Patients were included if they had functional motor symptoms as well as other mental health diagnoses or comorbid functional diagnosis like CFS or NES.

5.2.2.2 Matching

Once the search for FMD patients reached saturation, and all corresponding data were collected, the control group was established. Inclusion criteria for entry into the control group were:

I. Receipt of a psychiatric diagnosis from SLaM on the succeeding day the FMD patient received their diagnosis;
II. Only patients aged over-18 were included;
III. No evidence of a neurodegenerative disease of old age such as Alzheimer's disease or dementia;
IV. No diagnosis or evidence of an intellectual disability (F70 – F79); and
V. Patients were excluded who had only brief contact with mental health services but had no mental health diagnosis[6].

[6] Often such patients held diagnoses such as 'mental disorder, not otherwise specified' (F99), or 'Factors influencing health status and contact with health services' (Z00-Z99) diagnosis. It was decided these diagnoses did not denote a mental health disorder and so these patients were excluded.

The day after each FMD patient received their first SLaM diagnosis was searched in CRIS. This search returned any SLaM patient who had received a diagnosis on this particular day. A control group patient was then chosen at random from this list, using a random number generated from the website, random.org.

If they did not meet inclusion criteria a second patient was chosen using the same method and this process continued until each FMD patient was matched with two control group patients. Control patients were not matched on socio-demographic details as we were interested in the differences between groups on these particular factors.

5.2.2.3 Search strategy

Any SLaM patient suspected of having an FMD presentation was searched using the free-text fields in CRIS and the structured diagnostic search fields. The structured diagnostic search allowed for the search of all F44.4 primary and secondary diagnoses in SLaM. The free-text search allowed for a search of words linked to an FMD diagnosis on notes from routine clinical contact, Care Plan Approach reviews and any corresponding letters. See "Appendix 5.1: CRIS search criteria" for the search strategies used in our CRIS search and the total number of associated patients returned with each search. CRIS returns patient-level information.

Two points should be noted in relation to our search strategy. The first relates to the fact that one researcher read the detailed notes of all potential study participants. The most effective, but least efficient search strategy would be to read all 250,000 CRIS records. This would allow for a robust calculation of prevalence. Instead, given the time and resource limitations, as sensitive and specific a search as possible was employed. It is however possible, and indeed likely, that patients who did not receive an official diagnosis, or whose symptoms were described in the free-text with words not detected by our search, will not be included. In total, we conducted nine searches which appeared to reach saturation as new searches with additional terms did not return new patients. After each search, more duplicates were found until eventually no new search iteration produced new patients.

A second issue relates to the nature of the database. CRIS is updated every night and this means recently diagnosed FMD patients arriving into SLaM may be added each day. Our search does not include any patients referred after December 31st 2016.

677 potential functional motor patients were returned as possible participants. 208 (30.7%) of these were duplicate patients who had appeared in previous searches. These cases were removed.

122 patients did not meet the study's inclusion criteria. Half of these patients (46.3%) were excluded because they were aged under-18. Thirty-three patients were functional patients but there was no evidence that they displayed any motor symptoms, for example they experienced dissociative seizures only. In 32 patients, there was no evidence of any functional symptoms at all. Twenty-five patients were considered borderline cases. In these patients' notes there was a suggestion that they had a functional motor symptoms but their notes were not comprehensive enough for inclusion or they were awaiting updates from a neurologist. These cases were excluded. Figure 30 displays a flowchart showing the inclusion of participants.

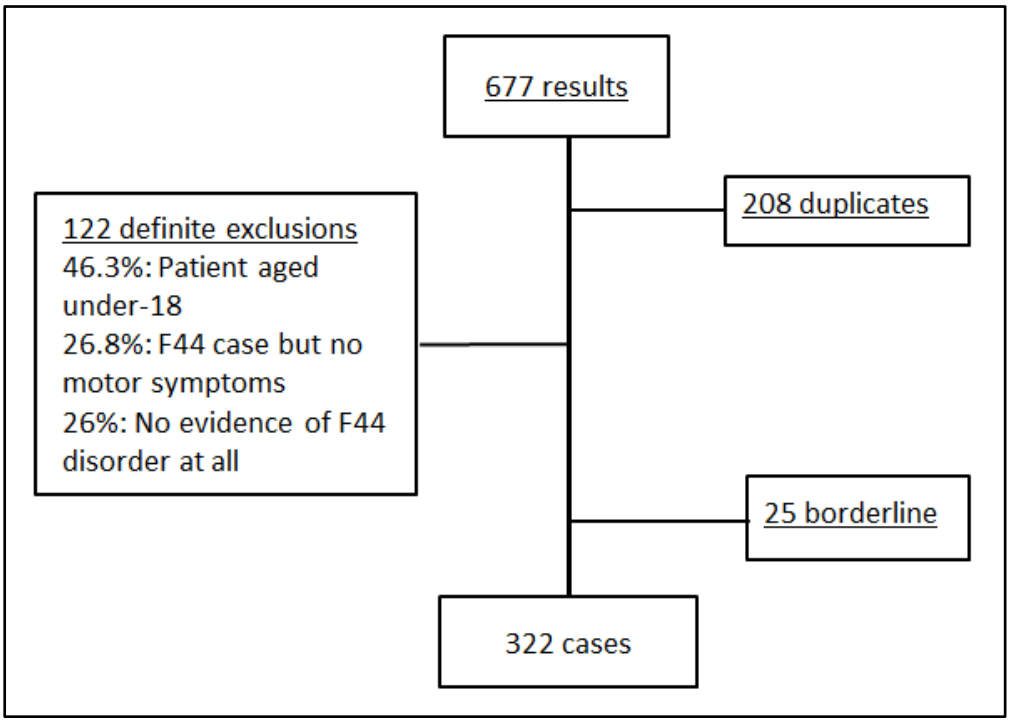

Figure 30 Flow chart showing functional motor disorder patients recruitment

In total, there were 322 functional motor cases for whom 644 control group participants were matched.

5.2.3 Measures

Data were taken from both unstructured and structured fields in CRIS. Unstructured fields include patients' notes, correspondence and events while structured CRIS fields include variables such as date of birth, clinical outcome scores and diagnoses.

Information was sought on the following variables: date of birth, gender, ethnicity, marital status, date of death, welfare benefits, housing status, employment status and title of most recently held job, pre-morbid employment status (yes, no, not known), age at psychiatric symptom onset, first, second and third primary and secondary diagnoses received by SLaM,

the nature of the motor symptoms (recorded qualitatively), lifetime use of mobility aids (yes, no, not known), psychiatric inpatient visits (number of inpatient spells and total number of days spent in hospital), Health of the Nation outcome scores (HoNOS) (first and last available from each record), Chronic Fatigue Questionnaire scores (first and last available), Physical Health Questionnaire (PHQ-9) scores (first and last available), comorbid physical conditions (experienced as an adult), exposure to childhood sexual and physical abuse (classified as abuse experienced under the age of 18; yes, no, not known), exposure to adult sexual or physical abuse (experienced over the age of 18; yes, no, not known), any comorbid functional motor symptoms, family history of mental health problems (yes, no, not known, type of relative and total number of relatives), complications at patient's birth (yes, no, not known and type of complication), most recent available information on smoking status (yes, no, not known) and most recent information on body mass index (BMI). Descriptive information was taken on any possible precipitating factors linked to symptom presentation. Precipitating factors are those defined by a clinician as potentially linked to patients' symptom onset and could include any event from childhood or adulthood.

For variables that could change over time, like smoking status, marital status, welfare benefits, housing status, and BMI scores, the most recent available information was collected.

The following sections outline more detail on some of the variables used in the study.

5.2.3.1 Abuse

Childhood sexual abuse (CSA) was classified according to the WHO Consultation on Child Abuse Prevention (1999) which states, "child sexual abuse is the involvement of a child in sexual abuse that he or she does not fully comprehend, is unable to give informed consent to, or for which the child is not developmentally prepared and cannot give consent, or that violates the laws or social taboos of society". Childhood physical abuse was defined according to the WHO's definition as "the intentional use of physical force against a child that results in, or has a high likelihood of resulting in, harm to the child's health, survival, development or dignity" (Butchart et al., 2006). There were instances where a patient described corporeal punishment as a child but did not perceive this as abuse or as harmful. These instances were not recorded as abuse. Adult physical or sexual abuse was defined in the same way but was classified as an event that occurred to a patient over the age of 18.

5.2.3.2 HoNOS

The HoNOS (Wing et al., 1998) has twelve items, each rated on a five-point scale by the attending clinician. The items cover aggression, self-harm, drug and alcohol abuse, cognitive

problems, physical illness and disability, hallucinations and delusions, depression, relationships, activities of daily living, residential environment and daytime activities. It includes five-point rating scales which range from 'zero' meaning 'no problems' to four, 'severe to very severe problems'. All items, with the exception of daytime activities, have shown good inter-observer agreement. The HoNOS are often operationalised as a composite twelve-item scale with a total HoNOS score ranging from 0-48. Internal consistency of the HoNOS is high and concurrent validity with other clinician-rated instruments is good (Pirkis et al., 2005).

5.2.3.3 HoNOS-ABI

HoNOS-ABI assesses the neuropsychiatric factors linked to brain damage. The scale correlates with established outcome measures such as post-injury employment (Coetzer & Toit, 2001). The inter-rater reliability for the HoNOS-ABI has been established as acceptable (Fleminger et al., 2005).

5.2.3.4 PHQ-9

The PHQ-9 allows clinicians to make diagnoses of depressive and other disorders. The questionnaire is used to monitor the severity of depression and patients' response to treatment. The questionnaire has good internal consistency and a test-retest reliability of 0.87. It has shown criterion validity with the Beck Depression Inventory (r = 0.79) (Zhang et al., 2013).

5.2.4 Statistical analysis

Descriptive statistics such as frequencies, means and standard deviations were used where appropriate. Normality of data was tested using histograms, box-plots, and the Kolmogorov-Smirnov and Shapiro-Wilk tests. FMD and control group patients were compared using Student's *t*-tests, Mann-Whitney-U tests, and Wilcoxon signed ranked tests to compare normally distributed and non-normal continuous data respectively. Odds ratios (OR) with 95% confidence intervals were used to compare groups where the rate of unknown information was known. Chi-square tests were used to compare frequencies between groups when the rate of unknown information was not known and differences in frequencies, rather than risk was assessed. A significance level of 5% (two-tailed) was used for all analyses. Separate binary logistic regression analyses were performed to assess the predictor variables related to a diagnosis of functional motor disorder, the variables related to the having a comorbid functional diagnosis in FMD patients alone and the variables related to a psychiatric hospital diagnosis in FMD patients only. A sensitivity analysis was conducted which removed any

patient with a schizophrenia-related diagnosis and comparisons were re-conducted. A binary logistic regression analysis was again conducted with the removal of all patients with a schizophrenia diagnosis to identify the variables related to a diagnosis of FMD.

All analyses were performed using Microsoft Excel (Microsoft Office Professional Plus 2010, Version 14.0.7015.1000) and SPSS V.21.0 for Windows (SPSS, Chicago, Illinois, USA). Graphs were created using GraphPad Prism (version 7.00 for Windows, La Jolla California, USA).

5.2.5 Ethical considerations

Ethical approval as an anonymised database for secondary analysis was granted in 2008, and renewed for a further five years in 2013 (Oxford C Research Ethics Committee, reference 08/H0606/71+5).

5.3 Results

In total there were 322 FMD patients and 644 control group participants.

5.3.1 Diagnoses

ICD-10 diagnostic information was gathered from the structured text in CRIS. The main primary and secondary diagnosis given by SLaM clinicians were assessed for both FMD and control groups. The primary diagnoses are outlined in Table 18.For FMD patients, the most commonly received main diagnoses were neurotic, stress-related or somatoform disorder diagnoses (F40-F48) (57.5% of patients), followed by an F99 ‘unspecified mental disorder’ diagnosis (12.7%) and ‘Z00-Z99’ diagnoses (11.8%). ‘Z00-Z99’ codes represent generic encounters a patient has with health services.

The control group represents a random sample of SLaM mental health patients and their ICD-10 diagnoses were distributed across a wider range of diagnostic categories. The most frequent diagnosis received by control group patients were mood disorders (F30 – F39) (22.7% of patients), followed by mental and behavioural disorders due to psychoactive substances (17.4%), and schizophrenia, schizotypal and delusional disorders (14%).

Some participants had received more than one primary diagnosis during their time in SLaM. If the second or third primary diagnosis they received was different to the first, this was

collected. These diagnoses are outlined in Table 91 (See "Appendix 5.2: Main diagnoses given in CRIS for FMD and control group patients")[7].

Table 18 Main SLaM diagnosis for functional motor and control groups

	Main SLaM diagnosis	
	Functional motor disorder n (%)	Control group n (%)
ICD-10 Diagnosis		
(F00-F09) Organic mental disorders	7 (2.2)	5 (0.8)
(F10-F19) Mental & behavioural disorders due to psychoactive substances	3 (0.9)	112 (17.4)
(F20 – F29) Schizophrenia, schizotypal and delusional disorders	4 (1.2)	90 (14)
(F30 – F39) Mood disorders	22 (6.8)	146 (22.7)
(F40 – F48) Neurotic, stress & somatoform disorders	185 (57.5)	70 (10.9)
(F50 – F59) Behavioural syndromes associated with physiological disturbances	2 (0.6)	17 (2.6)
(F60 – F69) Disorders of adult personality and behaviour	4 (1.2)	12 (1.9)
(F70 – F79) Intellectual disabilities	0 (0)	1 (0.2)
(F80 – F89) Disorders of psychological development	0 (0)	2 (0.3)
(F90 – F98) Behavioural and emotional disorders with onset in childhood and adolescence	0 (0)	14 (2.2)
(F99) Unspecified mental disorder	41 (12.7)	73 (11.3)
Other Diagnoses		
(FXX)	9 (2.8)	4 (0.6)
No axis one disorder	0 (0)	3 (0.5)
(Z00 – Z99) Factors influencing health status and contact in health services	38 (11.8)	89 (13.8)
(F00-F99) Mental, behavioural & neurodevelopmental disorders	2 (0.6)	2 (0.3)
(G00-G99) Diseases of the nervous system	2 (0.6)	0 (0)
(M00-M99) Diseases of the musculoskeletal system & connective tissue	2 (0.6)	0 (0)
(B20 – B24) Human immunodeficiency virus (HIV)	0 (0)	1 (0.2)
(X60 – X84) Intentional self-harm	0 (0)	1 (0.2)
(R00-R09) Symptoms, signs and abnormal clinical and lab findings	1 (0.3)	2 (0.3)
Total	322 (100)	644 (100)

All secondary diagnoses were recorded. Ninety-six FMD patients (29.8%) had a secondary diagnosis recorded in CRIS's structured diagnostic fields and 19 patients had more than one secondary or additional diagnosis. 176 (27.3%) control group patients had a secondary diagnosis and 59 had more than one secondary diagnosis.

Assessing the frequency of individual diagnoses, rather than individual patients, there was a statistically significant difference between rates of secondary diagnoses. There was a significantly higher proportion of psychoactive substance disorders in the control group than FMD group (38.3% versus 4.3%, χ^2: 45, 95% CI: 25.7 – 41.2, $p < 0.05$), and a higher rate of

[7] It is worth noting that due to the search strategy we employed whereby we assessed unstructured text, not all FMD patients will necessarily have received an F44 diagnosis.

neurotic, stress-related and somatoform secondary diagnoses amongst FMD patients compared to control group patients (47% versus 18.3%, χ^2: 31.6, 95% CI: 17.8 – 39.3, $p < 0.05$).

There were no other significant differences in the occurrence of secondary diagnoses between patients. Table 19 outlines patients' comorbid secondary diagnoses.

Table 19 Secondary diagnoses for functional motor disorder and control group participants

	Functional motor disorder n (%)	Control group n (%)	χ^2	95% CI	*p* value
ICD-10 Diagnosis					
(F00-F09) Organic, including symptomatic mental disorders	3 (2.6)	6 (2.6)	0	-5 – 3.6	> 0.05
(F10-F19) Mental and behavioural disorders due to psychoactive substances	5 (4.3)	90 (38.3)	45	25.7 – 41.2	**0.001**
(F20 – F29) Schizophrenia, schizotypal & delusional disorders	3 (2.6)	12 (5.1)	1.2	-2.9 – 6.7	> 0.05
(F30 – F39) Mood (affective) disorders	33 (28.7)	51 (21.7)	2.1	-2.9 – 17.5	> 0.05
(F40 – F48) Neurotic, stress-related and somatoform disorders	54 (47)	43 (18.3)	31.6	17.8 – 39.3	**0.001**
(F50 – F59) Behavioural syndromes associated with physiological disturbances and physical factors	2 (1.7)	3 (1.3)	0.09	-2.4 – 4.9	> 0.05
(F60 – F69) Disorders of adult personality and behaviour	9 (7.8)	24 (10.2)	0.5	-5 – 8.6	> 0.05
(F80 – F89) Disorders of psychological development	2 (1.7)	2 (0.9)	0.4	-1.9 -5.3	> 0.05
(F90 – F98) Behavioural and emotional disorders with onset in in childhood and adolescence	3 (2.6)	4 (1.7)	0.3	-2.4 – 5.9	> 0.05
(F99) Unspecified mental disorder	1 (0.9)	0 (0)	2.1	-0.9 – 4.8	> 0.05
Total	115 (100)	235 (100)			

19 functional motor patients and 59 control patients had more than one secondary diagnosis

5.3.1.1 SLaM diagnostic teams

The SLaM psychiatric services who first gave each ICD-10 diagnoses were assessed using structured field diagnostic data. This information was not available from structured fields in 38.5% of FMD patient cases and 64.6% of control group participants, representing a significant difference in the rate of unknown information (χ2: 28.9, 95% CI: 16.4 – 35.3, $p < 0.05$). It is possible that this information was unknown in cases that dated back to the inception of CRIS.

For FMD patients, the most common team giving the initial diagnosis were neuropsychiatry services in psychiatric and general hospital outpatients (39.9%), followed by neuropsychiatry liaison services in general hospital inpatient settings (17.7%) and liaison psychiatry services in inpatient settings (12.6%).

For control patients, the most frequent teams to give the first diagnosis were liaison psychiatry services in inpatient settings (20.2%), A&E (14.9%), drug and alcohol intervention services (11%), and assessment and liaison neighbourhood teams and assessment and brief treatment

teams (11%). The services from which patients received their first diagnosis are outlined in Table 92 (See "Appendix 5.3: List of teams giving first SLaM diagnoses").

5.3.2 Socio-demographics

5.3.2.1 Gender, ethnicity and marital status

There were 238 females (73.9%) and 84 males (26%) in the FMD group. FMD patients were more likely to be female than control group patients (OR: 2.52, 95% CI: 1.9 – 3.4, p = 0.001).

British participants constituted 64.6% of the FMD group, compared to 53.3% of the control group (OR: 1.6, 95% CI: 1.2-2.1, p = 0.001). There were more Irish participants (OR: 0.15, 95% CI: 0.04 – 0.7, p = 0.01) and more African, Caribbean and Black participants (OR: O.5, 95% CI: 0.3 – 0.7, p = 0.001) in the control than FMD group.

In 6.2% of cases in the FMD and 4.5% of the control group, ethnicity was not recorded.

The marital status of patients was compared. These data were the latest available from unstructured text within CRIS. Any changes in marital status were therefore not captured. In both the FMD and control groups, the marital status of 2.8% of the participants was unknown.

FMD patients were more likely to be married or in a civil partnership (41.5%) than control group patients (15.2%) (OR: 4, 95% CI: 2.9 – 5.4, p = 0.001). When stratified by gender, both male and female FMD patients were more likely to be married than control group counterparts. 38.8% of female FMD patients were married compared to 16.7% of female control patients (OR: 3.2, 95% CI: 2.14 – 4.7, p = 0.001). 49.4% of male FMD patients were married compared to 13.5% of male control group patients (OR: 6.2, 95% CI: 3.6 – 10.8, p = 0.001).

Amongst non-married participants, the most common status amongst FMD patients was singledom (68.3% of unmarried functional participants), followed by divorcees (18.6%) and cohabiting participants (6%). Table 20 outlines the gender, ethnicity and marital status of FMD and control group patients.

Table 20 Age, ethnicity and marital status for functional motor and control groups

		Functional motor disorder n (%)	Control group n (%)	OR	95% CI	*p* value
Gender	Female	238 (73.9)	341 (53)	2.52	1.9 – 3.4	**0.001**
	Male	84 (26.1)	303 (47)			
Ethnicity	British[1]	195 (64.6)	328 (53.3)	1.6	1.2 – 2.1	**0.001**
	Irish[2]	2 (0.7)	22 (3.6)	0.15	0.04 – 0.7	**0.01**
	Any other white background[2]	16 (5.3)	46 (7.5)	0.6	0.3 – 1.06	> 0.05
	Any other mixed background[2]	0 (0)	3 (0.9)	0.2	0.01 – 4.7	> 0.05
	African, Caribbean & Black[2]	43 (14.2)	152 (24.7)	0.5	0.3 – 0.7	**0.001**
	African	16 (37.2)	63 (41.4)			
	Caribbean	13 (30.2)	38 (25)			
	Any other black background	14 (32.6)	51 (33.6)			
	Asian[2]	14 (4.6)	24 (3.9)	0.98	0.5 – 1.9	> 0.05
	Indian	3 (21.4)	2 (8.3)			
	Pakistani	3 (21.4)	5 (20.8)			
	Bangladeshi	1 (7.1)	4 (16.7)			
	Chinese	1 (7.1)	2 (8.3)			
	Any other Asian background	6 (42.9)	11 (45.8)			
	Any other ethnic group[2]	32 (10.6)	40 (6.5)	1.3	0.8 – 2.2	> 0.05
	Total	302 (100)	615 (100)			
	Not known	20 (6.2)	29 (4.5)			
Marital status	Married or civil partner[3]	130 (41.5)	95 (15.2)	4	2.9 – 5.4	**0.001**
	Not married	183 (58.5)	531 (84.8)			
	Total	313 (100)	626 (100)			
	Married females[4]	90 (38.8)	55 (16.7)	3.2	2.14 – 4.7	**0.001**
	Married males[5]	40 (49.4)	40 (13.5)	6.2	3.6 -10.8	**0.001**
	Single	125 (68.3)	399 (75.1)			
	Divorced or civil partnership dissolved	34 (18.6)	54 (10.2)			
	Cohabiting	11 (6)	16 (3)			
	Widowed or surviving civil partner	9 (4.9)	27 (5)			
	Separated	4 (2.2)	35 (6.6)			
	Not known	9 (2.8)	18 (2.8)			

[1] Reference group: all other ethnicities
[2] Reference group: British
[3] Reference group: Not married
[4] Reference group: Unmarried females
[5] Reference group: Unmarried males

5.3.2.2 Age and mortality

Date of birth was collected from structured fields. For anonymity purposes, CRIS gives the month and year of birth but not the day of birth. Age at the time of analysis was calculated. In instances where a patient died, their age at death was used instead. When available, age at symptom onset was collected from unstructured text.

Mean age at analysis for FMD patients was 46.1 years (SD = 13.4) while for control patients it was 47.6 years (SD = 16.2). There was no statistically significant difference in age at analysis between groups. See Table 21 for a breakdown of mean age in both groups.

Table 21 Age at analysis, age at psychological symptom onset and mortality rates for functional motor and control groups

		Functional motor disorder	Control group	OR	95% CI	*p* value
Age	Mean age at analysis[1] (SD)	46.1 (13.4)	47.6 (16.2)		-3.4 – 4.2	> 0.05
	Mean age of symptom onset[1] (SD)	33.2 (14.6)	32.5 (17.8)		-1.4 – 2.9	> 0.05
	Female age of symptom onset[1] mean (SD)	32.2 (14.6)	32.7 (18)		-3.3 – 2.3	> 0.05
	Male age of symptom onset[1] mean (SD)	35.9 (14.2)	32.2 (17.7)		-0.4 – 7.8	> 0.05
Mortality	Observed deaths[2] n (*%*)	8 (2.5)	54 (8.4)	0.28	0.13 – 0.59	**0.001**
	Standardised mortality ratio[3]	3.10	3.83			
	Female[4] n (*%*)	5 (2.1)	25 (7.3)	0.27	0.1 – 0.7	**0.009**
	Male[5] n (*%*)	3 (3.6)	29 (9.6)	0.35	0.1 – 1.2	> 0.05
	Married/civil partner[6] n (%)	2 (1.4)	11 (9.9)	0.13	0.03 – 0.6	**0.01**
	Single, divorced, widowed, separated[7] n (%)	6 (3.5)	43 (8.3)	0.39	0.17 – 0.95	**0.04**
	Physical health condition[8] n (%)	7 (3.2)	45 (13.8)	0.2	0.09 – 0.5	**0.0001**
	No physical health condition[9] n (%)	0 (0)	3 (1.4)	0.41	0.02 – 8.1	> 0.05
	Smoker[10] n (%)	3 (4.3)	17 (8.3)	0.5	0.14 – 1.8	> 0.05
	Non-smoker[11] n (%)	2 (1.8)	13 (10.4)	0.16	0.03 – 0.7	**0.02**
Age v mortality	Mean age at death[1] (SD)	58.7 (13.7)	65.7 (19)		-20.9 – 7.1	> 0.05
	Female[1] mean age (SD)	53.8 (15.6)	70.3 (20.4)		-36 - 3	> 0.05
	Male[1] mean age (SD)	67 (2)	61.7 (17)		-1.6 - 12	> 0.05

[1] Independent samples t-test comparing mean age
[2] Reference: Surviving participants
[3] Standardised for gender and age using data from ONS 2015 for England and Wales
[4] Reference: Surviving females
[5] Reference: Surviving males
[6] Reference: Surviving married/civil partnership patients
[7] Reference: Surviving single/divorced/widowed/separated patients
[8] Reference: Surviving patients with physical health condition
[9] Reference: Surviving patients with no physical health conditions
[10] Reference: Surviving smokers
[11] Reference: Surviving non-smokers

The mean age at which FMD patients first began experiencing psychiatric symptoms was 33.2 years (SD: 14.6, range: 2 - 75) and for control patients it was slightly younger at 32.5 years (SD: 17.8, range 5 - 96). This information was taken from unstructured fields in CRIS. The difference between these age groups was not statistically significantly different. There were no statistical differences in symptom onset when stratified by gender. Table 21 outlines the age of symptom onset for both patient groups.

The proportion of participants who died in both groups was observed. This information was taken from the structured field in CRIS. In total, eight FMD (2.5%) and 54 control patients (8.4%) had died when data were collected. Using odds ratios to compare the mortality rates between groups, morality was higher in the control than FMD group (OR: 0.28, 95% CI: 0.13 – 0.59, $p = 0.001$).

Using indirect standardisation, a standard mortality ratio (SMR) was calculated for the FMD and control groups. The data were standardised by age and gender using Office for National Statistics (2015) mortality statistics for England and Wales. The SMR for FMD patients was

3.10, three times higher than the mortality rate seen in the general public in England and Wales but control patients SMR was higher again, at 3.83.

Mortality rates were explored further through the stratification of socio-demographic factors. When stratified by gender, females in the control group had a higher odds of mortality than females in the FMD group (OR: 0.27, 95% CI: 0.1 – 0.7, $p = 0.009$) but there was no significant difference in mortality risk between males in either group (OR: 0.35, 95% CI: 0.1 – 1.2, $p > 0.05$). Control group participants had a higher mortality rate compared to their counterparts in the FMD group regardless of marital status. If a comorbid physical health condition was present, control group participants had a higher risk of mortality compared to FMD patients (OR: 0.2, 95% CI: 0.09 – 0.5, $p = 0.001$), but no differences emerged between patients with no physical health condition. For smokers, there was no difference in the mortality rates between groups, but for non-smokers, control group patients had a higher risk of mortality compared to the FMD group (OR: 0.16, 95% CI: 0.03 – 0.7, $p = 0.02$).

The mean age at death in the FMD group was 58.7 years of age (SD: 13.7) and 65.7 years of age (SD: 19) in the control group but there was no statistically significant difference in age between groups. There were no statistical differences in mean age at death when stratified by gender. Table 21 outlines these morality rates.

Information was not routinely available on the cause of death.

5.3.2.3 Housing

The most recent type of accommodation resided in by patients was recorded when available from unstructured fields in CRIS. This information was unavailable in 25.2% of functional disorder cases and 14.3% of control group cases.

The most frequent type of housing in which FMD patients resided was privately owned accommodation, and FMD patients were significantly more likely to reside in a privately owned home than control group participants (OR: 2.8, 95% CI: 1.8 – 4.4, $p = 0.001$). Conversely, control group participants were more likely to be council tenants than FMD patients (OR: 0.6, 95% CI: 0.4 – 0.9, $p = 0.01$). There were no other observed differences in the type of dwelling resided in by either group.

There were no differences between groups in rates of patients living with families or friends or those privately renting or in sheltered or supported accommodation. Table 22 outlines the housing types of functional motor and control group patients.

Table 22 Table showing housing type for functional motor and control group participants

	Functional motor disorder n (%)	Control group n (%)	OR	95% CI	*p* value
Housing type					
Council tenant[1]	47 (19.5)	153 (27.7)	0.6	0.4 – 0.9	**0.01**
Homeless orhostel[2]	7 (2.9)	46 (8.3)	0.5	0.2 – 1.2	> 0.05
Living with family[2]	39 (16.2)	85 (15.4)	1.5	0.9 – 2.5	> 0.05
Living with friend[2]	4 (1.7)	7 (1.3)	1.9	0.5 – 6.6	> 0.05
Privately owned[2]	83 (34.4)	95 (17.2)	2.8	1.8 – 4.4	**0.001**
Privately rented[2]	53 (22)	117 (21.2)	1.5	0.9 – 2.3	> 0.05
Sheltered accommodation[2]	3 (1.2)	9 (1.6)	1.1	0.3 – 4.2	> 0.05
Supported accommodation[2]	5 (2.1)	40 (7.2)	0.4	0.2 – 1.1	> 0.05
Total	241 (100)	552 (100)			
Not known	81 (25.2)	92 (14.3)			

[1] Council tenant versus all other groups
[2] Reference: council tenant

5.3.2.4 Employment and benefits

The most recently available data on employment from structured fields was assessed. Structured employment fields in CRIS were often not up-to-date. This information was cross-checked with information from unstructured fields and where there was no agreement between structured and unstructured fields, the most recently available information was used.

Overall, the rate of unemployment was 60% in both groups but FMD patients were more likely to be in employment than patients in the control group (24.5% versus 17.4%, OR: 1.5, 95% CI: 1.1 – 2.2, $p = 0.02$). Control patients were more likely to be retired (OR: 0.3, 95% CI: 0.2 – 0.7, $p = 0.001$) while FMD patients were more likely to be medically retired (OR: 5.2, 95% CI: 1.4 – 19.4, $p = 0.02$).

Employment was stratified by gender, but no differences between groups emerged.

Information was collected on whether patients had been employed before their symptoms began (classified as pre-morbid employment). FMD patients were more likely to have been employed prior to the onset of their symptoms than control patients (OR: 2.34, 95% CI: 1.4 – 19.4, $p = 0.001$). Rates of pre-morbid employment were examined in currently unemployed patients. Currently unemployed FMD patients were more likely to have been employed pre-morbidly (82.9%) than currently unemployed control group patients (69.3%) (OR: 2.14, 95% CI: 1.4 – 3.3, $p = 0.001$).

Control group patients were more likely to receive welfare benefits (55.7%) than FMD patients (47.8%) (OR: 0.73, 95% CI: 0.55 – 0.96, $p = 0.03$). No differences emerged when stratified by

gender although FMD males had a higher rate of unemployment compared to FMD females. Table 23 outlines the employment and benefit status of FMD and control group patients.

Table 23 Table showing employment and benefits status of functional motor control group patients

		Functional motor disorder n (%)	Control group n (%)	OR	95% CI	*p* value
Work	Employed[1]	73 (24.5)	104 (17.4)	1.5	1.1 – 2.2	**0.02**
	Unemployed	179 (60.1)	389 (60.4)	1		
	Retired[2]	15 (5)	62 (10.4)	0.3	0.2 – 0.7	**0.001**
	Sick leave[2]	9 (3)	10 (1.7)	1.3	0.5 – 3.3	> 0.05
	Student[2]	11 (3.7)	23 (3.9)	0.7	0.3 – 1.5	> 0.05
	Voluntary work[2]	0 (0)	5 (0.8)	0.1	0.01 – 2.4	> 0.05
	Medically retired[2]	11 (3.7)	3 (0.5)	5.2	1.4 – 19.4	**0.02**
	Total	298 (100)	596 (100)			
	Not known	24 (7.5)	48 (7.5)			
Work v gender	Employed female[3]	58 (30)	61 (23.5)	1.4	0.9 – 2.2	> 0.05
	Employed male[4]	15 (25.9)	43 (18.5)	1.5	0.7 – 3	> 0.05
Pre-morbid work	Employed pre-morbidly[5]	246 (87.5)	385 (75)	2.34	1.6 – 3.5	**0.001**
	Currently unemployed but employed pre-morbidly[6]	170 (82.9)	284 (69.3)	2.14	1.4 – 3.3	**0.001**
	Total	281 (100)	513 (100)			
	Not known	41 (12.7)	131 (20.3)			
Benefits	Receives benefits[7]	143 (47.8)	337 (55.7)	0.73	0.55 – 0.96	**0.03**
	Receives benefits-female[8]	98 (44.5)	160 (50.3)	0.79	0.56 – 1.12	> 0.05
	Receives benefits-male[9]	45 (57)	177 (61.7)	0.82	0.5 – 1.4	> 0.05
	Total	299 (100)	606 (100)			
	Not known	23 (7.1)	39 (6.1)			

[1] Reference: unemployed
[2] Reference: employed
[3] Reference: unemployed females
[4] Reference: unemployed males
[5] Reference: not employed pre-morbidly
[6] Reference: unemployed now and unemployed pre-morbidly
[7] Reference: not receiving benefits
[8] Reference: females not receiving benefits
[9] Reference: males not receiving benefits

Of patients receiving benefits, the type of benefit received by the patient was assessed whenever that information was available in either structured or unstructured CRIS text (see Table 24). FMD patients were more likely to receive Disability Living Allowance (DLA) ($\chi 2$ = 17.7, *df* = 1, *p* = 0.001). DLA is a tax-free benefit for disabled people who need help with mobility or care costs. FMD patients were less likely to be in receipt of Income Support Allowance ($\chi 2$ = 4.9, *df* = 1, *p* = 0.03), a benefit commonly given to individuals who are pregnant, carers or lone parents with children under five or who are unable to work because they are sick or disabled.

Table 24 Type of benefits received by functional motor and control groups

	Functional motor disorder n (%)	Control group n (%)	χ2	95% CIs	*p* value
Disability Living Allowance	75 (43.6)	71 (24.7)	17.7	9.6 – 28.1	**0.001**
Employment Support Allowance[1]	44 (26.7)	84 (29.3)	0.4	-6.3 – 11.2	> 0.05
Housing Benefit	20 (11.6)	48 (16.7)	2.2	-1.9 – 11.6	> 0.05
Income Support Allowance	15 (8.7)	46 (16)	4.9	0.7 – 13.4	**0.03**
Child Benefit	6 (3.5)	11 (3.8)	0.03	-4.1 – 3.9	> 0.05
Carer's Allowance	6 (3.5)	2 (0.7)	-	-	**-**
Job Seeker's Allowance	5 (2.9)	16 (5.6)	1.8	-1.7 – 6.6	> 0.05
Freedom Pass*	1 (0)	7 (2.4)	-	-	-
Personal Independence Payment*	0 (0)	2 (0.7)	-	-	-
Total	172 (100)	287 (100)			

[1] Formerly Incapacity Benefit

* Unable to run chi-squared test on cell counts with less than five

The most recent information available on job type was assessed and categorised based on the industry in which the patient worked. Information on job type was collected for patients on their current role and, for patients now unemployed, information on their most recently held job was collected.

The type of industry in which patients worked or had worked was known in 74% of FMD cases and 55.7% in control group patients. See Table 25 for a breakdown of employment across industries.

The most common industry in which FMD patients were employed was administration, banking and project management. There were no differences in employment industries except for those employed or previously employed in the health industry and in social care. FMD patients were more likely to work in health industries (5.9% versus 2%, OR: 2.6, 95% CI: 1.2 - 5.9, p = 0.02) and social care industries (6.2% versus 2.5%, OR: 2.2, 95% CI: 1.02 – 4.8, p = 0.04).

Table 25 Employment rates of functional motor and control group patients according to occupational sector

	Functional motor disorder n (%)	Control Group n (%)	OR	95% CI	*p* value
Art, music & sport[1]	10 (3.1)	19 (3)	0.9	0.4 – 2.2	> 0.05
Child care[1]	8 (2.5)	7 (1.1)	2	0.7 – 6	> 0.05
Civil service[1]	10 (3.1)	10 (1.6)	1.8	0.7 – 4.7	> 0.05
Cleaning services[1]	6 (1.9)	15 (2.3)	0.7	0.3 – 2	> 0.05
Construction[1]	18 (5.6)	33 (5.1)	1	0.5 – 2	> 0.05
Customer services[1]	5 (1.6)	4 (0.6)	2.4	0.6 – 8.8	> 0.05
Design[1]	3 (0.9)	5 (0.8)	1.1	0.2 – 4.7	> 0.05
Education[1]	23 (7.1)	20 (3.1)	2	0.99 – 4.2	> 0.05
Factory[1]	5 (1.6)	10 (1.6)	0.9	0.3 – 2.8	> 0.05
Food, Drink & Hospitality[1]	16 (5)	36 (5.6)	0.8	0.4 – 1.6	> 0.05
Gardening[1]	1 (0.3)	4 (0.6)	0.4	0.05 – 4.1	> 0.05
Hair & beauty[1]	4 (1.2)	12 (1.9)	0.6	9.2 – 1.9	> 0.05
Health[1]	19 (5.9)	13 (2)	2.6	1.2 – 5.9	**0.02**
Mental health[1]	5 (1.6)	6 (0.9)	1.5	0.4 – 5.2	> 0.05
Nursing[1]	12 (3.7)	10 (1.6)	2.1	0.8 – 5.4	> 0.05
Administration, banking, project management[2]	36 (11.2)	64 (9.9)	0.8	0.5 – 1.3	> 0.05
Police, prison & army[1]	9 (2.8)	8 (1.2)	2	0.7 – 5.6	> 0.05
Retail[1]	24 (7.5)	47 (7.3)	0.9	0.5 – 1.7	> 0.05
Sex work[1]	0 (0)	1 (0.2)	0.6	0.02 – 14.8	> 0.05
Social care[1]	20 (6.2)	16 (2.5)	2.2	1.02 – 4.8	**0.04**
Transport[1]	5 (1.6)	19 (3)	0.5	0.2 – 1.4	> 0.05
Total	239 (74.2)	359 (55.7)			
Not known	38 (11.8)	156 (24.2)			
Not applicable	45 (14)	129 (20)			
Total	83 (25.8)	285 (44.3)			

[1] Reference group: Administration, banking, project management
[2] Reference group: all other industry professions

In the categorisations outlined in Table 25, types of employment in the health care sector included healthcare assistants, physiotherapists, occupational therapists but also non-clinical positions such as employment in medical records or hospital administration. In order to assess the difference in rates of those employed specifically in caring roles, a further analysis established care-giving employment. This denoted employment in positions involving responsibility for the health or well-being of another person.

In total, 19% of FMD patients and 8% of control patients were employed or had been employed in a care-giving role in health, social care, child care and mental health sectors, denoting a statistically significant difference (OR: 2.63, 95% CI: 1.73 – 4, $p = 0.001$).

When data was stratified by gender, the difference was only significant for females (OR: 2.04, 95% CI: 1.3 – 3.2, $p = 0.003$). Male FMD patients were proportionately more likely to work as a health or social care worker than male control patients, but no statistical significance emerged.

Patients were grouped according to whether they were carers to a family member or friend, either formally or informally. FMD patients were more likely to act as carers (9.8%) than control group participants (2.8%) (OR: 3.77, 95% CI: 2 – 7.1, *p* = 0.001). After stratification by gender, the significant difference remained for both males and females.

38.8% of FMD patients had a carer compared to 23.5% of control group participants. There was a significant difference between groups (OR: 2.06, 95% CI: 1.5 – 2.8, *p* = 0.001) and again, when data were stratified by gender both male and female FMD patients were more likely to have a carer than their control group counterparts.

Table 26 outlines the differences in social and health care work between groups as well as those working as carers to family and friends and the rates of patients with carers.

Table 26 Proportion of functional motor and control group patients working in social or health care, as carers to family or friends and patients with carers

	Functional motor disorder n (%)	Control group n (%)	OR	95% CIs	*p* value
Social or health care worker	54 (19)	46 (8.2)	2.63	1.73 – 4	**0.001**
Not known	38 (11.8)	83 (12.9)			
Female social or health worker[1]	48 (22.7)	37 (12.6)	2.04	1.3 – 3.2	**0.003**
Male social or health worker[2]	6 (8.2)	9 (3.4)	2.6	0.9 – 7.5	> 0.05
Carer to family or friends	28 (9.8)	16 (2.8)	3.77	2 – 7.1	**0.001**
Not known	37 (11.5)	75 (11.6)			
Female carer[3]	22 (10.4)	10 (3.3)	3.4	1.5 – 7	**0.002**
Male carer[4]	6 (8.1)	6 (2.2)	3.9	1.2 – 12.4	**0.02**
Patients with carers	107 (38.8)	128 (23.5)	2.06	1.5 – 2.8	**0.001**
Not known	46 (14.3)	100 (15.5)			
Females with a carer[5]	84 (41)	74 (26.2)	1.95	1.3 – 2.9	**0.001**
Males with a carer[6]	23 (32.4)	54 (20.6)	1.85	1.0 – 3.3	**0.04**

[1]Reference: Females who are not social/health workers
[2]Reference: Males who are not social/health workers
[3]Reference: Females who are not carers
[4]Reference: Males who are not carers
[5]Reference: Females without carers
[6]Reference: Males without carers

This study utilised the International Standard Classification of Occupations (ISCO-08), a system of employment categorisation developed by the International Labour Organisation. The criteria used are based on the skill level and specialisation required to perform tasks and duties of positions (International Labour Organisation, 2011). The system defines ten occupational groups, with each group assigned a skill level required to complete the job.

FMD patients were more likely to be technicians or associate professionals ($\chi 2 = 7.8$, *df* = 1, *p* = 0.005), less likely to be employed as plant or machine operators ($\chi 2 = 6.8$, *df* = 1, *p* = 0.01) or to

work in elementary professions ($\chi 2 = 7.8$, $df = 1$, $p = 0.005$). See Table 93 ("Appendix 5.4: Employment rates categorised according to ISCO-08 criteria").

5.3.3 Health

5.3.3.1 Functional motor symptomatology

The type of motor symptom affecting FMD patients was collected. This information was collected from unstructured fields within CRIS. Based on the information collected, nine symptom categorises were created including, 'weakness', 'tremor, spasms, jerks, and tics', 'non-back pain', 'numbness, paraesthesia, sensory loss', 'gait disturbance and falls', 'paralysis', 'back pain', 'urinary/faecal incontinence' and 'other sensory or motor issues'. The final 'other' group was a catch-all category which included issues which could not be easily defined by the other issues. Examples of 'other' symptoms included buzzing in the ear, restlessness, 'muzziness' in the head, dizziness, fainting, aphonia, speech difficulties, anosmia, and visual disturbance.

In nine cases, there was no information available on patients' symptoms, despite them having an F44.4 diagnosis. Of the remaining 313 patients, the mean number of functional symptoms was 2.42 (SD: 1.1, range 1 – 6).

The most commonly reported symptom was 'weakness', accounting for 50.3% of all reported symptoms, followed by 'other sensory or motor issues' (37.9%) and 'tremor, spasms, jerks and tics' (33.9%). See Figure 31 for a breakdown of the frequency of symptoms.

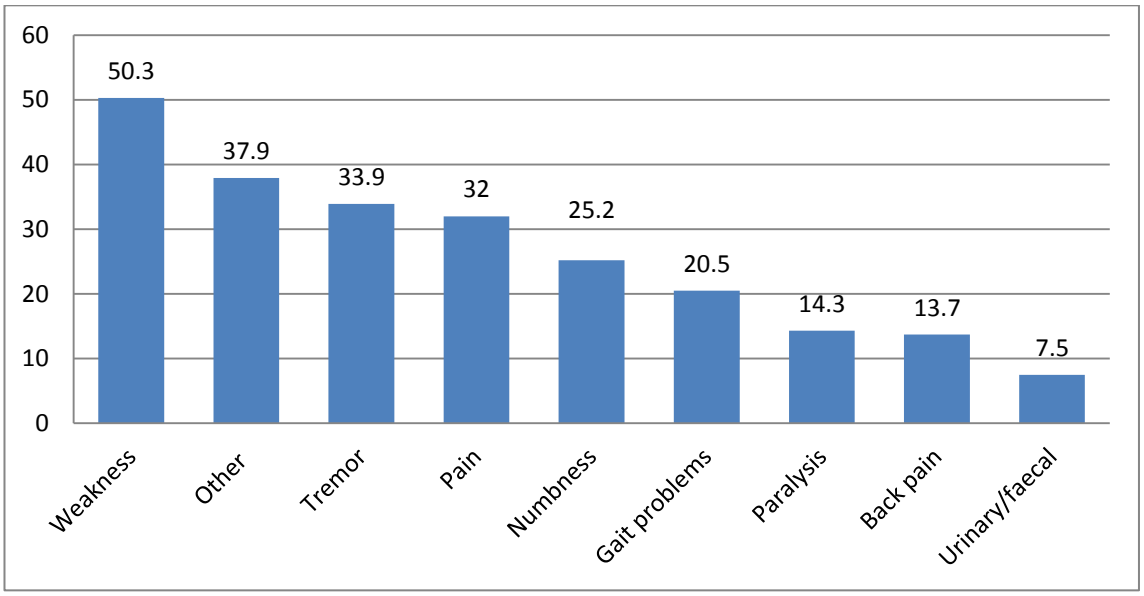

Figure 31 Frequency of symptom types in functional motor disorder patients

When assessed according to socio-demographic variables, non-back pain was associated with the highest proportion of females (79.6%). The eldest participants were those experiencing gait problems or falls (M: 50.7 years, SD: 13).

Whether the patients had a comorbid physical health condition was assessed. The lowest rate of comorbid health conditions were amongst those with back pain (58.1%), while the highest rate was amongst patients with gait problems or falls.

Psychiatric admission rates were highest in those with paralysis and urinary or faecal problems. Mobility aid use was highest in those with urinary/faecal incontinence, followed by back pain.

When those who were bed-bound were assessed, the highest proportion was in those who were paralysed. Child abuse rates were highest in those with urinary or faecal problems, followed by paralysis.

See Table 27 for a breakdown of socio-demographic variables associated with different functional symptoms.

Table 27 Type and frequency of FMD symptoms according to psychosocial variables

	Total n (%)	Female n (%)	Mean age (SD)	Physical health condition n (%)	Psychiatric admission n (%)	Mobility aid user n (%)	Bed-bound n (%)	Child sexual abuse n (%)
Weakness	162 (50.3)	122 (75.3)	44.6 (13)	116 (75.8)	55 (34)	100 (69)	11 (7.5)	25 (19.1)
'Other'	122 (37.9)	92 (75.4)	48.6 (14)	86 (74)	31 (25.4)	53 (50.5)	6 (5.7)	17 (17.5)
Tremor	109 (33.9)	82 (75.2)	45.3 (14)	74 (72.5)	41 (37.6)	48 (50.5)	6 (6.3)	21 (23.6)
Non-back pain	103 (32)	82 (79.6)	46.9 (12)	75 (75)	37 (35.9)	64 (66.7)	7 (7.3)	18 (21.7)
Numbness	81 (25.2)	60 (74.1)	43.5 (12)	53 (67.9)	24 (29.6)	47 (62.7)	2 (2.7)	14 (21.2)
Gait problems	66 (20.5)	51 (77.3)	50.7 (13)	49 (80.3)	27 (40.9)	38 (65.5)	3 (5.3)	10 (19.2)
Paralysis	46 (14.3)	34 (73.9)	40.8 (12)	33 (75)	30 (65.2)	30 (71.4)	5 (11.6)	10 (25)
Back pain	44 (13.7)	30 (68.2)	46.9 (13)	25 (58.1)	19 (43.2)	30 (75)	3 (7.5)	5 (13.9)
Urinary/faecal	24 (7.5)	20 (83.3)	44.4 (10)	18 (75)	15 (62.5)	20 (87)	1 (4.3)	6 (30)

If there was any mention in the unstructured notes of fatigue, anxiety, low mood or depression this was noted and a comparison was made between the FMD and control groups. It is important to note that this was a qualitative, post-hoc analysis.

Fatigue was more common in the FMD group (OR: 4.5, 95% CI: 2.7 – 12.8, p = 0.001) and this significant difference applied to males and females. There was no difference in the mean age of patients suffering from fatigue between the two groups.

There was no difference in the rate of reported anxiety between the two groups and no difference when gender and age were compared.

Depression was higher in the control group than the FMD group (OR: 3, 95% CI: 2.7 – 12.8, p = 0.001) and higher amongst female control group members. There was no difference when only males were examined. There were also no differences in the mean age of FMD and control group patients experiencing depression. See Table 28 for a breakdown of fatigue, anxiety and low mood in the FMD and control groups.

Table 28 The rate of mentions of fatigue, anxiety and low mood as a comorbid symptom in the functional motor and control groups

	Functional motor disorder n (%)	Control group n (%)	OR	95% CI	*p* value
Fatigue[1]	25 (7.8)	9 (1.4)	4.5	2.7 – 12.8	**0.001**
Female[2]	18 (7.7)	7 (2.1)	3.9	1.6 – 9.7	**0.002**
Male[3]	7 (8.8)	2 (0.7)	14.4	2.9 – 71	**0.001**
Mean age[4]	45.8 (11)	43.9 (15)		-7.5 -11.3	>0.05
Anxiety[1]	56 (17.4)	98 (15.2)	1.2	0.8 – 1.7	> 0.05
Female[2]	40 (17.2)	57 (16.7)	1.03	0.6 – 1.6	> 0.05
Male[3]	16 (20)	41 (13.5)	1.5	0.8 -2.8	> 0.05
Mean age[4]	43.7 (14)	45.5 (16)		- 6.7 -3	> 0.05
Depression[1 5]	112 (34.8)	288 (44.7)	3.3	0.5 – 0.9	**0.003**
Female[2]	81 (34.7)	158 (46.3)	0.6	0.4 – 0.9	**0.006**
Male[3]	16 (19)	41 (13.5)	1.5	0.8 – 2.8	> 0.05
Mean age[4]	46.8 (13.5)	48.6 (17)		-5 –1.4	> 0.05

[1] Reference: patients with no mention of symptom in notes
[2] Reference: females with no mention of symptom in notes
[3] Reference: males with no mention of symptom in notes
[4] Independent *t*-test
[5] Includes low mood, suicide ideation and suicide attempts

The rate of depression, anxiety and fatigue and their co-occurrence with functional symptoms was assessed (see Table 29 for all frequency rates). Depression was most likely to co-occur in back pain (43.2% of those with back pain also reported depression), while the lowest rate of depression occurred within gait problems and falls (31.8%).

Regarding anxiety, there were lower rates generally than depression, with 17.4% of FMD patients with any mention of anxiety in their notes. For those with back pain, anxiety was the lowest rate (11.4% of those with back pain had a mention of anxiety), while the highest rate of anxiety was in patients with weakness and numbness (19.8% in both).

Fatigue had the lowest frequency amongst paralysis patients when it was only mentioned in one case while it was most commonly reported in patients with urinary or faecal problems occurring in three cases.

Table 29 Table showing rate of depression, anxiety and fatigue within each symptom type

	Depression present n (%)	Anxiety present n (%)	Fatigue present n (%)
Urinary or faecal problems	8 (33.3)	3 (12.5)	3 (12.5)
Weakness	64 (39.5)	32 (19.8)	13 (8)
Numbness	29 (35.8)	16 (19.8)	5 (6.2)
Other sensory or motor issues	42 (34.4)	22 (18)	9 (7.4)
Tremor, spasms, jerks and tics	39 (35.8)	20 (18.3)	8 (7.3)
Back pain	19 (43.2)	5 (11.4)	2 (4.5)
Non-back pain	33 (32)	16 (15.3)	11 (10.7)
Paralysis	16 (34.8)	6 (13)	1 (2.2)
Gait problems, falls	21 (31.8)	13 (19.7)	6 (9.1)

5.3.3.2 Mobility

The lifetime prevalence of any kind of mobility aid use was assessed for only FMD patients from the unstructured fields in CRIS.

Over half the sample had in the past, or continued to use, a mobility aid (163 patients, 58.2%). Of these patients, 108 (66.3%) used a wheelchair while the remainder used a Zimmer frame or walking stick (33.7%). Of all FMD patients, 19 patients (6.7%) were or had been completely bedbound. Of the FMD patients who had received a psychiatric inpatient admission, 76.3% used a walking aid, while 23% did not.

See Table 30 for an overview of the mobility aids and bedbound rates of FMD patients.

Table 30 Lifetime mobility aid use in functional motor disorder patients

	Functional motor disorder n (%)
Mobility aid	163 (58.2)
Wheelchair user	108 (66.3)
Zimmer frame or walking stick	55 (33.7)
No mobility aid	117 (41.8)
Not known	42 (35)
Total	322 (100)
Bedbound	19 (6.7)
Not bedbound	263 (93.3)
Not known	40 (12.4)
Total	322 (100)

5.3.3.3 Smoking rates and BMI scores

The last recent information available on smoking status was collected from unstructured CRIS records. In practise, this meant that if a patient smoked for a number of years but gave up before the end of their CRIS record they were recorded as a 'non-smoker'. Smoking status was unknown in 43.5% of FMD patients and 51.4% of control patients.

From the available data, 38.5% of FMD patients were active smokers, less than the 62.2% of smokers amongst control group patients (OR: 0.38, 95% CI: 0.26 – 0.55, p = 0.001). This is higher than the rate within the English public which is 19% (Health and Social Care Information Centre, 2015). Both female and male control group patients were significantly more likely to smoke than their FMD counterparts. There was no difference in the age of smokers, smoking rates between employed patients or those with no comorbid physical condition. However, unemployed control group patients and those patients with a physical health condition were more likely to smoke than their FMD counterparts. See Table 31 for a breakdown of smoking rates between groups by socio-demographic variables.

Table 31 Smoking rates and mean BMI scores for functional motor disorder and control group patients

	Functional motor disorder n (*%*)	Control group n (*%*)	OR	95% CIs	*p* value	Rate in English adult public
Smoking						
Yes	70 (38.5)	206 (62.2)	0.38	0.26-0.55	**0.001**	19%*
No	112 (62.5)	125 (37.8)				81%*
Not known	140 (43.5)	331 (51.4)				
Female smokers[1]	46 (34.6)	91 (53.8)	0.45	0.3 – 0.7	**0.001**	17%*
Male smokers[2]	24 (34.8)	115 (55.8)	0.4	0.2 – 0.8	**0.005**	24%*
Mean age smokers[3] (SD)	45.2 (12.3)	45.9 (14)		-4.5 - 3	> 0.05	
Employed [4]	12 (32.4)	14 (32.6)	0.9	0.4 - 2.5	> 0.05	19%*
Unemployed [5]	46 (41.1)	165 (73.3)	0.25	0.2 – 0.4	**0.001**	35%*
Physical health condition present	49 (35.3)	116 (60.7)	0.35	0.2 – 0.6	**0.001**	
No physical health condition	19 (50)	69 (62.7)	0.6	0.3 – 2.3	> 0.05	
BMI normal range (18.5 – 24.9)						
Mean [3] (SD)	28.2 (8.8)	26.8 (6.7)		-1.1 – 3.9	> 0.05	25.6**
Not known	260 (64)	486 (75.5)				
Female mean[3] (SD)	27.7 (9)	27.7 (8)		-3 - 3	> 0.05	26.9
Male mean[3] (SD)	30.3 (6)	25.8 (5)		1.2 – 7.9	**0.008**	27.4
Age (Pearson's *r*)	0.19	0.022			> 0.05	
Employed mean[3] (SD)	19.3 (2.9)	25.2 (8)		-12.3 – 0.5	> 0.05	
Unemployed mean[3] (SD)	29.6 (9)	27.6 (7)		- 1 – 5.1	> 0.05	
Physical health condition mean (SD)	29.8 (9)	27.1 (7)		-0.08 – 5.4	> 0.05	
No health condition mean (SD)	21.4 (6)	26.5 (6)		-9 – (-1.2)	**0.01**	

[1] Female smokers versus female non-smokers
[2] Male smokers versus male non-smokers
[3] Independent samples *t*-test (unequal variance assumed)
[4] Employed smokers versus employed non-smokers
[5] Unemployed smokers versus unemployed non-smokers; excludes 'retired', 'medically retired', 'sick leave, 'student', & 'voluntary work' groups
* Health and Social Care Information Centre (2015)
** Health Survey for England data from 2011 (Sperrin et al., 2016)

The most up-to-date information was taken on BMI scores. This information was taken from the unstructured and structured fields, depending on which was the most recent.

There was no significant difference in mean BMI scores between FMD and control patients although both groups' mean BMI scores were above the normal limit (t = 1.5, df = 90.8, two-tailed p = 0.135). BMI scores were available for 62 FMD and 158 control group patients.

There was no significant difference in BMI scores between females however male FMD patients had significantly higher BMI scores compared to male control patients (t = 2.7, df = 86, two-tailed p = 0.01). There was no correlation between age and BMI scores for the FMD group (r = 0.2, n = 62, p > 0.05), or for the control group (r =0.02, n = 158, p > 0.05). There was no difference in BMI scores between employed groups, unemployed groups, or between patients with a physical health condition. Amongst patients with no physical health condition, control group patients had significantly higher BMI (t = -2.6, df = 63, two-tailed p = 0.01). See Table 31 for a breakdown of BMI scores between groups and their associated socio-demographic variables.

5.3.3.4 Comorbid physical conditions

Information from unstructured CRIS notes was taken on whether patients had a comorbid physical health condition. Physical health conditions were classified as any physical health problem the patient suffered from in their recent medical history.

In total, 74.5% of FMD patients had a current or recent physical health problem compared to 59.6% of control group patients (OR: 1.9, 95% CI: 1.4 – 2.7, p = 0.001).

Information was stratified by socio-demographic variables. Female FMD patients were more likely to have a physical health condition than female control patients (OR: 2.2, 95% CI: 1.5 – 3.3, p = 0.001), but there was no difference between male groups. The mean age of FMD patients with a physical health condition was 47.4 years (SD: 14), significantly younger than the mean age of control group patients with a physical health condition (mean: 53.2 years, SD: 17, df = 527, p = 0.001).

Both employed and unemployed FMD patients were more likely to have a comorbid physical health condition compared to controls, as well as patients who had had a psychiatric stay and those who did not. Non-smoker FMD patients had a higher rate of physical health conditions than non-smoking control group patients but there was no difference in the rate of physical health conditions between smokers.

The number of physical health conditions was counted for each patient. The mean number of physical health conditions for FMD patients was 2.27 (SD: 1.6) and this did not differ significantly from the control patients. When the mean number of physical symptoms was assessed by gender, no differences emerged. The number of reported comorbid physical

conditions was significantly positively correlated with age for both FMD (r = 0.34, p < 0.05) and control group (r = 0.38, p < 0.05). See Table 32 for a breakdown of the rate of physical health conditions and the associated socio-demographic factors.

Table 32 Comorbid physical disease rates and mean number of comorbid physical conditions for the functional motor and control groups

	Functional motor disorder n (%)	Control group n (%)	OR	95% CI	*p* value
Comorbid physical condition	219 (74.5)	326 (59.6)	1.9	1.4 – 2.7	**0.001**
Not known	28 (8.7)	97 (15.1)			
Females with physical condition[2]	168 (77.1)	173 (60.1)	2.2	1.5 – 3.3	**0.001**
Males with physical condition[3]	51 (67.1)	153 (59.1)	1.4	0.8 – 2.4	> 0.05
Physical illness mean age (SD)	47.4 (14)	53.2 (17)		-8.5 – (-3.3)	**0.001**
Employed	45 (70.3)	38 (40.9)	3.4	1.7 – 6.7	**0.001**
Unemployed	131 (76.6)	205 (59.8)	2.5	1.4 – 4.2	**0.001**
Psychiatric inpatient stay	84 (79.2)	155 (60.8)	0.7	0.48 – 0.97	**0.03**
No psychiatric inpatient stay	135 (71.8)	171 (58.6)	1.8	1.2 – 2.7	**0.003**
Smoker	49 (72.1)	116 (62.7)	1.5	0.8 – 2.8	> 0.05
Non-smoker	90 (82.6)	75 (64.7)	2.6	1.4 – 4.8	**0.003**
Mean number of comorbid physical conditions[4] (SD)	2.27 (1.6)	2.12 (1.5)		- 0.12 – 0.4	> 0.05
Female[4] mean (SD)	2.3 (1.5)	2.2 (1.5)		- 0.19 – 0.46	> 0.05
Male[4] mean (SD)	2.08 (1.7)	2.04 (1.6)		- 0.5 – 0.6	> 0.05

[1] Comorbid physical illness versus no comorbid physical illness
[2] Females with comorbid physical illness versus females without comorbid physical illness
[3] Males with comorbid physical illness versus males without comorbid physical illness
[4] Independent *t*-test

Types of physical health conditions were categorised and coded according to the ICD-10 classification system. The most common type of physical health condition experienced by FMD patients was 'diseases of the nervous system' (22.2% of all physical conditions) followed by 'endocrine, nutritional and metabolic diseases' (15.3%) and diseases of the circulatory system (12.4%).

Statistically significant differences in rates occurred in three of the fifteen disease categories. Control group participants (6.8% of patients with a physical health condition) were more likely to experience 'infectious and parasitic diseases' than FMD patients (OR: 0.3, 95% CI: 0.14 – 0.6, p = 0.002). FMD patients were more likely to experience 'diseases of the nervous system' compared to 7% in the control group (OR: 1.9, 95% CI: 1.2 – 3.1, p = 0.007). FMD patients were also more likely to experience 'congenital malformations, deformations and chromosomal abnormalities' compared to control group patients (OR: 16.8, 95% CI: 2.1 – 132.5, p = 0.007). Table 33 outlines the breakdown of ICD-10 codes across both groups.

Table 94 and Table 95 give a breakdown of socio-demographic differences between patients with infectious and parasitic diseases and patients with congenital malformations as there was

also a significant difference in rates between these groups (see "Appendix 5.5: Rate of diseases in functional motor and control groups").

Table 33 Type of physical health conditions in the functional motor disorder group and control group

ICD-10 code	Functional motor disorder n (%)	Control group n (%)	OR	95% CI	*p* value
(A00-B99) Certain infectious and parasitic diseases[1]	10 (2.1)	46 (6.8)	0.3	0.14 – 0.6	**0.002**
(C00-D49) Neoplasms[1]	15 (3.1)	32 (4.7)	0.7	0.3 – 1.3	> 0.05
(D50-D89) Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism[1]	15 (3.1)	16 (2.4)	1.3	0.6 – 2.8	> 0.05
(E00-E89) Endocrine, nutritional and metabolic diseases[2]	74 (15.3)	104 (15.3)	1.1	0.8 – 1.5	> 0.05
(G00-G99) Disease of the nervous system[1]	107 (22.2)	48 (7)	1.9	1.2 – 3.1	**0.007**
(H00-H95) Diseases of the eye, adnexa, ear and mastoid process[1]	9 (1.9)	12 (1.8)	1.05	0.4 – 2.6	> 0.05
(I00-I99) Disease of the circulatory system[1]	60 (12.4)	105 (15.5)	0.8	0.5 – 1.2	> 0.05
(J00-J99) Diseases of the respiratory system[1]	41 (8.5)	70 (10.3)	0.8	0.5 – 1.3	> 0.05
(K00-K95) Diseases of the digestive system[1]	37 (7.6)	69 (10.2)	0.7	0.4 – 1.2	> 0.05
(L00-L99) Disease of the skin and subcutaneous tissue[1]	19 (3.9)	31 (4.6)	0.8	0.5 – 1.6	> 0.05
(M00-M99) Diseases of the musculoskeletal system and connective tissue[1]	36 (7.5)	75 (11.1)	0.7	0.4 – 1.1	> 0.05
(N00-N99) Disease of the genitourinary system[1]	31 (6.4)	31 (4.6)	1.4	0.8 – 2.5	> 0.05
(Q00-Q99) Congenital malformations, deformations and chromosomal abnormalities[1]	12 (2.5)	1 (0.15)	16.8	2.1 – 132.5	**0.007**
(R00-R99) Symptoms, signs and abnormal clinical and lab findings, not elsewhere classified[1]	16 (3.3)	31 (4.6)	0.7	0.4 – 1.4	> 0.05
(S00-T88) Injury, poisoning and certain other consequences of external causes[1]	1 (0.2)	7 (1)	0.2	0.02 – 1.7	> 0.05
Total	483 (100)	678 (100)			

[1] Reference: Endocrine, nutritional and metabolic diseases
[2] Reference: All other disorders

Given the high proportion of nervous system diseases amongst FMD patients, a further analysis assessed the occurrence of diseases affecting the nervous system in more detail. Ninety-seven individual FMD participants experienced neurological disease, with a total of 107 instances of neurological disease across patients.

Amongst these patients, the most common type of disorder of the nervous system was headache, accounting for 61.7% of all 107 instances of nervous system diseases. Of patients with headache, 87.9% were women and the average age was 45.7 years (SD: 11). Within nervous system diseases no significant differences in gender rates or mean age were observed between functional motor and control group patients. Table 34 outlines the frequencies of diseases of the nervous system in FMD and control group patients.

Table 34 Diseases of the nervous system for the functional motor and control groups

	Functional motor disorder n (%)	Control group n (%)	OR	95% CI	*p* value
Diseases of the nervous system*	107 (22.2)	48 (7)			
Female[1]	80 (82.5)	21 (48.8)	4.9	2.2 – 10.9	**0.001**
Mean age[2]	47.2 (13)	59.2 (19)		- 18.4 – (-4.7)	**0.001**
(G20-G26, G30-G32) Extrapyramidal and movement disorders & other degenerative diseases	1 (0.9)	7 (14.6)			
Female[1]	1 (100)	4 (57.1)	2.3	0.07 – 76	> 0.05
Mean age[2]	-	3 (42.9)			
(G35-G37) Demyelinating diseases of the central nervous system	3 (2.8)	4 (8.3)			
Female[1]	3 (100)	3 (75)	3	0.1 – 102	> 0.05
Mean age[2]	59 (12.2)	50 (18)		-22 – 40	> 0.05
(G40) Epilepsy	15 (14)	11 (22.9)			
Female[1]	11 (73.3)	5 (45.5)	3.3	0.6 - 17	> 0.05
Mean age[2]	46.1 (11)	48.5 (16)		-13.2 – 8.6	> 0.05
(G40-G47) "Non-specific seizures"	3 (2.8)	5 (10.4)			
Female[1]	1 (33.3)	0 (0)			
Mean age[2]	52 (13)	49 (13.5)		- 21 - 27	> 0.05
(G43) Headache	66 (61.7)	7 (15.2)			
Female[1]	58 (87.9)	5 (71.4)	2.9	0.5 – 17.5	> 0.05
Mean age[2]	45.7 (11)	52.9 (13)		-17 - 3	> 0.05
(G45) Transient cerebral ischaemic attacks	2 (1.8)	3 (6.5)			
Female[1]	2 (100)	1 (33.3)	8.3	0.2 – 320	> 0.05
Mean age[2]	63 (17)	79 (16)		-64- 31	> 0.05
(G47) Sleep disorder	2 (1.8)	1 (2.2)			
Female[1]	2 (100)	1 (100)			
Mean age[2]	54 (8)	56		-134 - 130	> 0.05
(G50-G59, G60-G65, G70-G73) Nerve, nerve root and plexus disorders, polyneuropathies and other disorders of the peripheral nervous system and diseases of myoneural junction and muscles	6 (5.6)	9 (18.8)			
Female[1]	1 (16.7)	3 (33.3)	0.4	0.03 – 5	> 0.05
Mean age[2]	52.5 (17)	60.1 (20)		-29.2 – 14	> 0.05
(G80-G83) Cerebral palsy and other paralytic syndromes	4 (3.7)	-			
Female[1]	3 (75)	-			
Mean age[2]	40 (14)	-			
(G89-G99) Other disorders of the nervous system	5 (4.7)	1 (2.1)			
Female[1]	4 (80)	-			
Mean age[2]	36.8 (9)	58		- 50 - 7	> 0.05

* 107 neurological diseases across 97 FMD patients & 48 neurological diseases across 43 control patients

[1] Reference: Males

[2] Independent samples *t*-test

5.3.3.5 Comorbid functional disorders

Information on comorbid functional disorders was collected from unstructured notes and structured diagnostic fields. In total, 106 patients (32.9%) had a comorbid functional disorder, classified as functional symptoms other than motor symptoms (see Table 35). FMD patients

were more likely to have a comorbid functional disorder than control group patients (OR: 26, 95% CI: 14 – 48.2, $p = 0.001$).

Under half of FMD patients with a comorbid functional disorder had NES (41.2%). The next most common functional disorder was IBS (19.4%) followed by dissociative pain disorder (also often frequently described as somatoform pain disorder) in 11.3% of patients.

Table 35 The rate and type of comorbid disorders in the functional motor and control groups

	Functional motor group n (%)	Control group n (%)	OR	95% CI	*p* value
Comorbid functional disorder?*					
Yes[1]	106 (33.8)	12 (1.9)	26	14 – 48.2	**0.001**
No	208 (66.2)	612 (98.1)			
Total	314 (100)	624 (100)			
Not known	8 (2.5)	20 (3.1)			
Females with comorbid functional disorder[2]	81 (34.6)	10 (3)	17	8.6 – 33.8	**0.001**
Males with comorbid functional disorder[3]	25 (31.3)	2 (0.7)	65	15.2 – 286.3	**0.001**
If comorbid functional disorder, what?					
Chronic fatigue syndrome	11 (8.9)	2 (14.3)			
Irritable bowel syndrome	24 (19.4)	7 (50)			
Fibromyalgia	11 (8.9)	3 (21.4)			
Non-epileptic seizures	51 (41.2)	1 (7.1)			
Dissociative pain disorder	14 (11.3)	0 (0)			
Somatoform disorder	6 (0)	0 (0)			
Other functional disorders	7 (5.6)	1 (7.1)			
Total	124 (100)	14 (100)			

* 18 FMD participants had more than one comorbid functional disorder; 2 control participants had more than one comorbid functional disorder

[1] Comorbid functional disorder versus no comorbid functional disorder

[2] Reference: females without comorbid functional disorder

[3] Reference: males without comorbid functional disorder

Assessing only FMD patients, a binary logistic regression analysis was conducted to assess whether there were any socio-demographic differences between FMD patients with a comorbid functional disorder and those who had functional motor symptoms only. Binary independent variables entered into the model included gender, ethnicity, marital status, psychiatric admission history, experience of CSA, comorbid physical health problems, smoking status, history of employment as a health or social care worker, having a carer, and employment status.

None of these independent variables predicted a comorbid functional disorder amongst FMD patients. The Cox and Snell pseudo *R*-square was 0.064 indicating that the fit of the model to the data was poor. See Table 100, "Appendix 5.8: Logistic regression results" for a full breakdown of the regression model.

5.3.3.6 Psychiatric inpatient stays

Information on admissions to psychiatric inpatient settings was collected from structured fields. Whether the patient had had an admission, how many times they were admitted and the total number of days spent in hospital was assessed.

In total, 107 (33%) FMD patients had received a hospital admission at the time of data collection compared to 43.5% of control group participants (OR: 0.65, 95% CI: 0.5 – 0.9, p = 0.002). When stratified by gender, there was no difference in admission rates between females, though male control group participants were more likely to have had a psychiatric admission than male FMD patients (OR: 0.44, 95% CI: 0.3 – 0.7, p = 0.002). There was no difference in rates between patients with a carer, but control patients with no carer were more likely to have had an admission than FMD patients with no carer. Control group smokers, and control group patients both receiving and not receiving benefits were more likely to have had an admission than their FMD patient counterparts.

Patients with no admissions were removed from the analysis and the number of days in hospital and the frequency of psychiatric admission spells were analysed. The number of days and the number of hospital spells data was positively skewed so a non-parametric analysis was conducted.

The mean number of inpatient days spent by FMD patients was 130.3 days (SD: 124) (median: 112 days, IQR: 89) but control group patients spent significantly more days in inpatient settings (mean: 143.4 days, SD: 209, median: 67, IQR: 155, U = 11944.5, p = 0.007). Control female patients spent significantly more days in inpatient settings than female FMD patients but there were no differences between male groups.

The mean number of episodes in hospital for FMD patients was 1.8 (SD: 3.7), significantly less than the mean number for control group patients at 3.3 (SD: 3.4, U = 8618.5, p = 0.001). Both male and female control group patients had a significantly higher number of admissions than their FMD counterparts. See Table 36 for a breakdown of the psychiatric admission rates and socio-demographic rates between groups as well as the number of days and hospital admissions.

Examining only FMD patients, a binary logistic regression model was employed and characteristics differentiating patients who had a psychiatric admission history were compared to those who had not been admitted to hospital. The regression model indicated being unemployed pre-morbidly (OR: 0.09, p = 0.01), using a walking aid (OR: 5.28, p = 0.002), not experiencing childhood physical abuse (OR: 0.18, p = 0.02), experiencing physical or sexual

abuse as an adult (OR: 6.8, p = 0.007), and being a current smoker (OR: 3.05, p = 0.02) significantly predicted psychiatric inpatient admission at the 5% level. The Cox and Snell pseudo R-square was 0.32 indicating that the fit of the model to the data was only moderate. See Table 101 ("Appendix 5.8: Logistic regression results").

Table 36 Psychiatric inpatient rates, days in hospital and spells in hospital for functional motor and control groups

		Functional motor disorder n (%)	Control group n (%)	OR	95% CI	p value
Inpatient stay	Yes[1]	107 (33)	280 (43.5)	0.65	0.5 – 0.9	**0.002**
	Female[2]	82 (34.5)	131 (38.4)	0.85	0.6 – 1.2	> 0.05
	Male[3]	25 (29.8)	149 (49.2)	0.44	0.3 – 0.7	**0.002**
	Patient has carer[4]	46 (43)	63 (49.2)	0.78	0.5 – 1.3	> 0.05
	Patient doesn't have carer[5]	51 (30.2)	194 (46.6)	0.49	0.3 – 0.7	**0.001**
	Receives benefits[6]	64 (44.8)	186 (55.2)	0.66	0.4 – 0.9	**0.04**
	Doesn't receive benefits[7]	33 (21.2)	87 (32.5)	0.56	0.4 – 0.9	**0.01**
No. of inpatient days	Mean (SD)[8]	130.3 (124)	143.4 (209)	11944.5		**0.007**
	Female mean (SD)[8]	138.2 (127.4)	154.8 (223)	4408		**0.04**
	Male mean (SD)[8]	102.8 (109.3)	133.4 (195)	1535.5		> 0.05
No. of inpatient spells	Mean (SD)[8]	1.8 (3.7)	3.3 (3.4)	8618.5		**0.001**
	Female mean (SD)[8]	2.01 (4.2)	3.5 (3.8)	3268		**0.001**
	Male mean (SD)[8]	1.1 (0.3)	3.0 (3.1)	1219.5		**0.001**

[1] Reference: Patients with no inpatient stay
[2] Reference: Females with no inpatient stay
[3] Reference: Males with no inpatient stay
[4] Reference: Patients with carers not admitted to psychiatric settings
[5] Reference: Patients without carers not admitted to psychiatric settings
[6] Reference: Patients receiving benefits with no inpatient stay
[7] Reference: Patients not receiving benefits with no inpatient stay
[8] Mann-Whitney U test

5.3.3.7 Familial mental health

From the unstructured CRIS text, any mention of family mental health problems was recorded. The information was not known in 82 (25.5%) FMD and 315 (49%) control patients.

There was a positive history of familial mental health problems in 52.1% of FMD patients, less than the 60% found for control patients. No statistical difference was observed between groups.

The maximum number of relatives with a reported mental health issue for control patients was five, and four for FMD patients. The mean number of relatives with a mental health disorder for FMD patients was 1.59 (SD: 0.9) and for the control group, the mean was slightly higher at 1.71 (SD: 1). There was no statistical difference between the groups.

Relatives with a reported mental health problem were compared between the groups. The most common relative reported to have mental health problem amongst FMD patients were mothers (accounting for 30.4% of relatives with a mental health problem), followed by fathers (18.2%) and patients' sons (6.1%). Similar patterns were observed in the control group and no differences in the rates were seen between groups. See Table 98 ("Appendix 5.6: History of familial mental health issues").

5.3.4 Life events

5.3.4.1 Physical and sexual abuse

Information on childhood and adulthood sexual or physical abuse was taken from unstructured text in CRIS.

No information was available on the presence or absence of CSA for 22.4% of FMD patients and 39.9% of control group patients. The rate of CSA in the FMD group was 20% which did not differ significantly from the rate of abuse reported in the control group at 21.9% (OR: 0.9, 95% CI: 0.6 – 1.3, $p > 0.05$).

Information on the presence or absence of childhood physical abuse (CPA) was lacking in 22% of FMD patients and 40.2% of control patients. The rate of CPA (22.7%) was slightly higher in the FMD group than that of sexual abuse within that group, but it did not differ significantly to the rate of CPA reported in the control group (21.8%) (OR: 1.05, 95% CI: 0.72 – 1.5, $p > 0.05$).

No information was available on adult physical or sexual abuse (APSA) for 20.2% of FMD patients and 37.9% of control group patients. The rate of APSA in FMD patients was 27.2% which did not significantly differ from the rate in the control group of 21% (OR: 1.4, 95% CI: 0.9 – 2, $p > 0.05$).

Each abuse variable was stratified for gender, employment, history of mental health problems in the family and patients' status as carers. There were no significant differences between groups on any of these variables, with the exception of APSA as control patients experienced more abuse if they also had a family history of mental health problems and FMD patients were more likely to experience ASPA if they had a carer.

See Table 37 for a breakdown of CSA, CPA and APSA abuse rates across groups.

Table 37 History of childhood sexual and physical abuse and physical or sexual abuse in adulthood in the functional motor and control group participants

	Functional motor disorder n (%)	Control group n (%)	OR	95% CI	*p* value
History of child sexual abuse	50 (20)	85 (21.9)	0.9	0.6 – 1.3	> 0.05
Not known	72 (22.4)	257 (39.9)			
Female[1]	43 (22.8)	66 (30.3)	0.7	0.4 – 1.1	> 0.05
Male[2]	7 (11.3)	19 (11.2)	1	0.4 – 2.5	> 0.05
Employed[3]	7 (11.9)	12 (16.9)	0.7	0.2 – 1.8	> 0.05
Unemployed[4]	43 (23.1)	72 (23.1)	1	0.7 – 1.5	> 0.05
Family mental health history[5]	29 (69)	39 (83)	0.46	0.17 – 1.2	> 0.05
Patient has a carer[6]	18 (20.9)	21 (22.8)	0.9	0.44 – 1.8	> 0.05
Patient doesn't have a carer[7]	28 (18.8)	55 (19.8)	0.94	0.57 – 1.6	> 0.05
History of child physical abuse	57 (22.7)	84 (21.8)	1.05	0.72 – 1.5	> 0.05
Not known	71 (22)	259 (40.2)			
Female[1]	46 (24.3)	58 (27.1)	0.9	0.6 – 1.4	> 0.05
Male[2]	11 (17.7)	27 (15.8)	1.2	0.5 – 2.5	> 0.05
Employed[3]	10 (16.9)	14 (19.7)	0.8	0.3 - 2	> 0.05
Unemployed[4]	45 (24.2)	70 (22.7)	1.1	0.7 – 1.7	> 0.05
Family mental health history[5]	32 (71.1)	39 (79.6)	0.6	0.24 – 1.6	> 0.05
Patient has a carer[6]	19 (21.8)	12 (13.3)	1.8	0.82 – 4	> 0.05
Patient doesn't have a carer[7]	33 (22.1)	66 (23.8)	0.9	0.6 – 1.4	> 0.05
History of adult physical or sexual abuse	70 (27.2)	84 (21)	1.4	0.9 – 2	> 0.05
Not known	65 (20.2)	244 (37.9)			
Female[1]	65 (33.9)	75 (32.8)	1.1	0.7 – 1.6	> 0.05
Male[2]	5 (7.7)	9 (5.3)	1.5	0.5 – 4.7	> 0.05
Employed[3]	13 (21)	14 (18.7)	1.2	0.5 – 2.7	> 0.05
Unemployed[4]	53 (28.2)	68 (21.4)	1.4	0.9 – 2.2	> 0.05
Family mental health history[5]	26 (50)	33 (75)	0.3	0.14 – 0.8	**0.014**
Patient has a carer[6]	25 (29.4)	15 (16.5)	2.1	1.0 – 4.4	**0.04**
Patient doesn't have a carer[7]	37 (24)	56 (19.6)	1.3	0.8 – 2.1	> 0.05

[1] Reference: Females not experiencing the relevant abuse
[2] Reference: Males not experiencing the relevant abuse
[3] Reference: Employed patients not experiencing the relevant abuse
[4] Reference: Unemployed patients not experiencing the relevant abuse
[5] Reference: Patients with family mental health history not experiencing the relevant abuse
[6] Reference: Patients with carers not experiencing the relevant abuse
[7] Reference: Patients without carers not experiencing the relevant abuse

5.3.4.2 Early life events

Information on possible symptom precipitants was collected from unstructured text in CRIS. Precipitants constituted any information written in the clinical notes that might explain symptom onset. No exclusion criteria were applied and similar to information on functional motor symptoms, events were categorised after data collection was complete. If there was any reference in a patient's clinical records of any possible precipitant, at any stage of their life, this was recorded and categorised. These categories were sub-divided into events that occurred in a patient's early life and those that occurred after the age of 18. As this analysis involves the categorisation of qualitative information following its collection from the medical

records, it is not possible to entirely ascertain whether an event did not occur at all or whether the information was not known. These results should therefore be viewed as preliminary.

Early life events included, 'left or abandoned by a parent as a child', 'witnessing violence between parents', 'parents divorcing or separating', 'in care, fostered or adopted as a child', 'experiencing bullying in primary or secondary school' and 'taking drugs under the age of 18'.

Statistically significant differences in the frequency of reported events were found in the experience of bullying in primary or secondary school where the rate was higher in the FMD (17.8%) than the control group (9.1%) (OR: 2.16, 95% CI: 1.4 – 3.3, p = 0.001). Following stratification, this significant effect remained for both men and women.

A significantly lower proportion of FMD patients reported taking drugs under the age of 18 (1%) than the rate reported amongst control group patients (6.6%) (OR: 0.15, 95% CI: 0.05 – 0.5, p = 0.002). This effect was significant only between female groups, not between men.

Table 38 outlines the rates in the type of early life events for functional motor and control group participants.

Table 38 Reported early life events in functional motor and control group patients

	Functional motor disorder n (%)	Control group n (%)	OR	95% CI	*p* value
Left or abandoned by a parent as a child[1]	30 (10.5)	37 (7.1)	1.5	0.9 – 2.5	> 0.05
Female[2]	25 (11.8)	24 (8.6)	1.4	0.8 – 2.6	> 0.05
Male[3]	5 (6.7)	13 (5.5)	1.2	0.4 – 3.6	> 0.05
Violence between parents[1]	15 (5.3)	31 (6)	0.87	0.46 – 1.6	> 0.05
Female[2]	12 (5.7)	19 (6.8)	0.8	0.4 – 1.8	> 0.05
Male[3]	3 (4)	12 (5)	0.8	0.2 – 2.9	> 0.05
Parents divorced or separated[1]	38 (13.2)	63 (12.2)	1.1	0.7 – 1.7	> 0.05
Female[2]	29 (13.6)	34 (12.1)	1.1	0.7 – 1.9	> 0.05
Male[3]	9 (12)	29 (12.2)	0.98	0.4 – 2.2	> 0.05
In care, fostered or adopted as a child[1]	14 (4.9)	35 (6.8)	0.7	0.4 – 1.3	> 0.05
Female[2]	10 (4.7)	20 (7.1)	0.6	0.3 – 1.4	> 0.05
Male[3]	4 (5.3)	15 (6.3)	0.8	0.3 – 2.6	> 0.05
Bullied in primary or secondary school[1]	51 (17.8)	47 (9.1)	2.16	1.4 – 3.3	**0.001**
Female[2]	37 (17.5)	26 (9.3)	2.1	1.2 – 3.5	**0.008**
Male[3]	14 (18.6)	21 (8.8)	2.4	1.1 – 4.9	**0.02**
Took drugs under-18[1]	3 (1)	34 (6.6)	0.15	0.05 – 0.5	**0.002**
Female[2]	2 (0.9)	15 (5.4)	0.17	0.04 – 0.7	**0.02**
Male[3]	1 (1.3)	19 (8)	0.2	0.02 – 1.2	> 0.05

[1] Reference: patients not experiencing the same event
[2] Reference: females not experiencing the same event
[3] Reference: males not experiencing the same event

5.3.4.3 Adult life events

Adult life events were categorised and explored in more detail. These categories include experiencing 'financial difficulties', 'bereavement' categorised as either a likely or unlikely symptom precipitant, 'workplace, school or university issues', 'involvement in a legal dispute', 'problems within a sexual relationship', 'experiencing an accident or assault' classed as either a likely or unlikely precipitant, 'being affected by war or political turmoil', 'being socially isolated', 'abusing drugs or alcohol', 'having a family member who is unwell', 'experiencing a physical symptom' classified as either a likely or unlikely precipitant or 'experiencing a complication before, during or after giving birth'. These categories were constructed after all data on precipitants was collected and are post-hoc and non-standardised.

There were no differences in rates between groups experiencing financial difficulties, social isolation, bereavement classified as either a likely precipitant (occurred shortly before the onset of psychiatric symptoms) or an unlikely precipitant (e.g. did not occur close to the onset of psychiatric symptoms), or the experience of a traumatic or complicated birth or post-natal complication like post-natal depression.

FMD patients experienced higher rates of workplace, school or university issues (22.6%) compared to control group participants (6.9%) (OR: 3.9, 95% CI: 2.5 – 6.1, p = 0.001), were more likely to be involved in a legal dispute (7% versus 0.8%, OR: 9.6, 95% CI: 3.3 – 28, p = 0.001), to report problems within a sexual relationship (32.1 versus 23.2%, OR: 1.6, 95% CI: 1.1 – 2.2, p = 0.006), to have experienced an accident or assault when it was classified as either a likely precipitant (15.3% versus 2.3%, OR: 7.6, 95% CI: 3.9 – 14.7, p = 0.001) or an unlikely precipitant (6.6% versus 1.7%, OR: 4, 95% CI: 1.8 – 8.9, p = 0.001), to be affected by war or political upheaval (6.9% versus 3.3%, OR: 2.2, 95% CI: 1.13 – 4.3, p = 0.02), to report a family member as being unwell (22% versus 6.4%, OR: 4.1, 95% CI: 2.6 – 6.5, p = 0.001) and to have had a physical symptom precipitating their symptom onset (23.3% versus 7.3%, OR: 3.8, 95% CI: 2.5 – 5.9, p = 0.001). FMD patients were significantly less likely to report abusing drugs or alcohol compared to the control group (8% versus 29%, OR: 0.2, 95% CI: 0.13 – 0.3, p =0.001).

Table 39 gives a breakdown of adult life events and gender rates between groups.

Table 39 Reported adult life events in functional motor and control group patients

	Functional motor group n (%)	Control group n (%)	OR	95% CI	*p* value
Financial difficulties (e.g. debt, homelessness)[1]	35 (12.2)	59 (11.4)	1.08	0.7 – 1.7	> 0.05
Female[2]	22 (10.4)	29 (10.3)	1	0.6 – 1.8	> 0.05
Male[3]	13 (17.3)	30 (12.6)	1.5	0.7 – 3	> 0.05
Bereavement but unlikely a precipitant[1]	49 (17.1)	64 (12.4)	1.5	0.97 -2.2	> 0.05
Female[2]	35 (16.5)	38 (13.6)	1.3	0.8 – 2	> 0.05
Male[3]	14 (18.7)	26 (10.9)	1.9	0.9 – 3.8	> 0.05
Bereavement as likely precipitant[1]	54 (18.8)	75 (14.5)	1.4	0.9 – 2	> 0.05
Female[2]	43 (20.3)	45 (16.1)	1.3	0.8 – 2.1	> 0.05
Male[3]	11 (14.7)	30 (12.6)	1.2	0.6 – 2.5	> 0.05
Workplace, school or university issues[1]	65 (22.6)	36 (6.9)	3.9	2.5 – 6.1	**0.001**
Female[2]	43 (20.3)	19 (6.8)	3.5	1.9 – 6.2	**0.001**
Male[3]	22 (29.3)	17 (7.1)	5.4	2.7 – 10.9	**0.001**
Involved in a legal dispute[1]	20 (7)	4 (0.8)	9.6	3.3 – 28	**0.001**
Female[2]	15 (7.1)	2 (0.7)	10.6	2.4 – 46.8	**0.002**
Male[3]	5 (6.7)	2 (0.8)	8.4	1.6 – 44.4	**0.01**
Problems within a sexual relationship (e.g. divorce)[1]	92 (32.1)	120 (23.2)	1.6	1.1 – 2.2	**0.006**
Female[2]	77 (36.3)	84 (30)	1.3	0.9 – 1.9	> 0.05
Male[3]	15 (20)	36 (15.1)	1.4	0.7 – 2.7	> 0.05
Accident or assault but unlikely a precipitant[1]	19 (6.6)	9 (1.7)	4	1.8 – 8.9	**0.001**
Female[2]	14 (6.6)	3 (1.1)	6.5	1.9 – 23	**0.004**
Male[3]	5 (6.7)	6 (2.5)	2.8	0.8 – 9.3	> 0.05
Accident or assault a likely precipitant[1]	44 (15.3)	12 (2.3)	7.6	3.9 – 14.7	**0.001**
Female[2]	30 (14.2)	2 (0.7)	22.9	5.4 – 97	**0.001**
Male[3]	14 (18.7)	10 (4.2)	5.2	2.2 – 12.4	**0.001**
Affected by war or political turmoil[1]	20 (6.9)	17 (3.3)	2.2	1.13 – 4.3	**0.02**
Female[2]	12 (5.6)	5 (1.8)	3.3	1.1 – 9.4	**0.03**
Male[3]	8 (10.7)	12 (5)	2.2	0.9 – 5.7	> 0.05
Socially isolated[1]	5 (1.7)	9 (1.7)	1	0.3 – 3	> 0.05
Female[2]	5 (2.4)	4 (1.4)	1.7	0.4 – 6.3	> 0.05
Male[3]	0 (0)	5 (2.1)	0.3	0.02 – 5.1	> 0.05
Abusing drugs or alcohol[1]	23 (8)	150 (29)	0.2	0.13 – 0.3	**0.001**
Female[2]	13 (6.1)	56 (20)	0.3	0.1 – 0.5	**0.001**
Male[3]	10 (13.3)	94 (39.5)	0.2	0.1 – 0.5	**0.001**
Family member unwell[1]	63 (22)	33 (6.4)	4.1	2.6 – 6.5	**0.001**
Female[2]	45 (21.2)	21 (7.5)	3.3	1.9 – 6	**0.001**
Male[3]	18 (24)	12 (5)	5.9	2.7 – 13	**0.001**
Physical symptom or diagnosis a possible precipitant[1]	67 (23.3)	38 (7.3)	3.8	2.5 – 5.9	**0.001**
Female[2]	53 (25)	17 (6.1)	5.2	2.9 – 9.2	**0.001**
Male[3]	14 (23)	21 (8.8)	2.4	1.1 – 4.9	**0.02**
Complication in pregnancy (e.g. postnatal depression, miscarriage or still birth)[1]	22 (10.4)	33 (11.7)	0.88	0.5 – 1.6	> 0.05

[1] Reference: patients not experiencing the event
[2] Reference: females not experiencing the event
[3] Reference: males not experiencing the event

5.3.5 Outcome scores

5.3.5.1 HoNOS

An analysis was conducted comparing overall HoNOS scores between FMD and control group patients. Participants from both groups were included in the analysis if they had two available HoNOS scores. The earliest and latest scores were used for each participant.

The first analysis assessed any potential within-group differences between participants who completed two HoNOS scores and those with one or no HoNOS scores. Most FMD patients had one or no scores (78.6%), while 69 patients (21.4%) had at least two available scores. 49.6% of control group participants had two available scores, while 50.3% of control group participants had one or no HoNOS score.

An analysis compared whether there were any within-group socio-demographic differences between patients with two complete HoNOS scores and those with one or none. No significant differences emerged for FMD patients, except for ethnicity. British FMD patients were more likely to have one or no complete HoNOS score than two or more (χ^2 = 12.6, 95% CI: 9.6 – 36.8, p = 0.0004). No within-group differences for control participants emerged when the same analysis was conducted (see Table 99, "Appendix 5.7: Socio-demographic differences between groups").

The mean number of days that passed between the first and last available HoNOS score was assessed. For FMD patients, the mean number of days were 1001.5 (SD: 1255, range: 12 – 5848), while the mean for control group patients was 1654.8 (SD: 1347, range: 1 – 5843), a statistically significant difference (t = -3.9, df = 104.7, p = 0.001). This suggests control patients were in the Trust for a longer period of time.

A repeated measures t-test found no statistically significant difference between the first HoNOS score (mean = 13.8, SD = 6.6) and last available mean HoNOS score (mean = 12.8, SD = 6.2) for the 69 FMD patients (t = 1.0, 95% CI -0.98 – 2.9, df = 68, p > 0.05). Results were stratified by gender, ethnicity, experience of CSA, employment and comorbid physical health problems and no differences over time emerged.

Control group participants saw a significant drop in mean scores over time (t = 6.4, 95% CI: 1.9 – 3.6, df = 319, p < 0.01). When control group participants' results were stratified by gender, ethnicity, experience of CSA employment and health, all HoNOS scores improved significantly according to these variables over time. However, control patients who were carers had no change in HoNOS scores.

Table 40 shows the change in HoNOS scores for FMD and control group participants as well as their socio-demographic variables.

Table 40 First and last available adjusted HoNOS scores for the functional motor and control groups

		First available HoNOS score mean (SD)	Last available HoNOS score mean (SD)	Mean diff	*t*-test	*p* value
Functional motor group (n = 69)		13.8 (6.6)	12.8 (6.2)	1	1.0	> 0.05
Gender	Female (n = 52)	14 (6.8)	13.1 (6.3)	1	0.81	> 0.05
	Male (n = 17)	13.4 (6.2)	12.1 (6.2)	1.3	0.63	> 0.05
Ethnicity	British (n = 29)	15.2 (7.7)	13.8 (6.3)	1.4	0.93	> 0.05
	Other ethnicity (n = 40)	12.9 (5.6)	12.2 (6)	0.7	0.53	> 0.05
CSA	Experienced CSA (n = 10)	14.9 (9.3)	13.5 (8.7)	1.4	0.7	> 0.05
	Didn't experience CSA (n = 41)	13.9 (6.9)	12.2 (5.1)	1.7	1.3	> 0.05
Work	Employed (n = 12)	10.3 (4.6)	10.9 (6.3)	- 0.7	-0.4	> 0.05
	Unemployed (n = 49)	14.5 (6.3)	13 (6.1)	1.4	1.1	> 0.05
	Patient is a carer (n = 7)	12.9 (3.2)	15 (4)	-2.1	-2.1	> 0.05
	Patient is not a carer (n = 56)	13.9 (7)	12.6 (6.2)	1.3	1.1	> 0.05
	Patient is a social/health worker (n = 7)	15.9 (7)	15.5 (7.5)	0.34	0.7	> 0.05
	Patient not a social/health worker (n = 54)	13.7 (6.7)	12.8 (5.8)	0.93	0.86	> 0.05
Health	Physical health problem (n = 46)	13.9 (6.1)	13.9 (6)	0	0.02	> 0.05
	No physical health problem (n = 22)	13.8 (7.8)	11 (6.3)	2.8	1.3	> 0.05
Control group (n = 320)		12.5 (6.2)	9.8 (5.8)	2.7	6.4	**0.001**
Gender	Female (n = 174)	12.2 (6.2)	9.5 (5.5)	2.7	4.8	**0.001**
	Male (n = 146)	12.8 (6.2)	10.1 (6)	2.7	4.3	**0.001**
Ethnicity	British (n = 158)	12.4 (6)	10.5 (6)	1.9	3.3	**0.001**
	Other ethnicity (n = 162)	12.5 (6)	8.98 (5.4)	3.52	5.8	**0.001**
CSA	Experienced CSA (n = 54)	12.5 (6)	10.1 (5.3)	2.4	2.5	**0.006**
	Didn't experience CSA (n = 172)	12.4 (6)	9.5 (5.6)	2.9	5.3	**0.001**
Work	Employed (n = 48)	12.5 (6.5)	8 (5.4)	4.5	4	**0.001**
	Unemployed (n = 236)	12.6 (6.4)	10.3 (5.7)	2.3	5.2	**0.001**
	Patient is a carer (n = 8)	13.8 (4.9)	13 (7)	0.8	0.3	> 0.05
	Patient is not a carer (n = 301)	12.4 (6)	9.6 (5.7)	2.8	6.4	**0.001**
	Patient is a social/health worker (n = 22)	14.2 (4.9)	7.7 (4.6)	6.5	4.6	**0.001**
	Patient not a social/health worker (n=287)	12.3 (6.2)	9.9 (5.8)	2.4	5.3	**0.001**
Health	Physical health problem (n = 167)	12.5 (5.8)	10 (5.6)	2.5	4.4	**0.001**
	No physical health problem (n=121)	12.1 (6.6)	9.4 (5.7)	2.7	3.7	**0.001**

Range: 0 (best) - 48 (worst)

A repeated measures one-way ANOVA was conducted to assess whether there was a change over time in HoNOS scores between groups. This test showed no significant interaction between FMD and control groups' adjusted HoNOS scores over time (F (1, 387) = 2.83, p = 0.093). Figure 32 represents the line graph showing the change in scores over time.

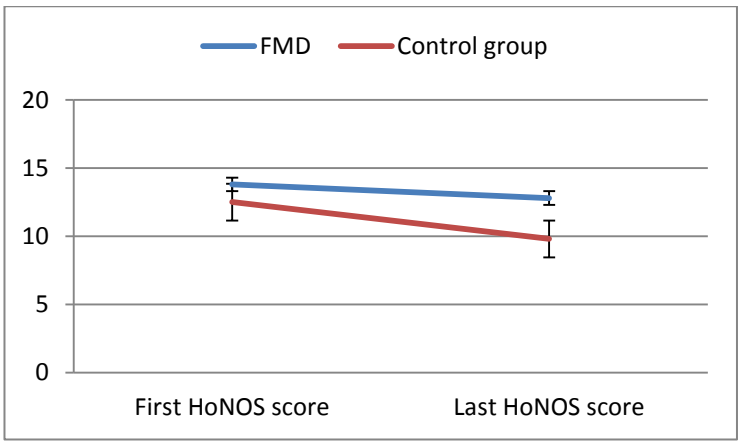

Figure 32 Functional motor and control group HoNOS scores and their change over time

5.3.5.2 HoNOS-ABI scores

Fifty-four FMD patients had two available HoNOS-ABI scores. Only two control group participants had two available HoNOS-ABI scores, so FMD patients' scores alone were analysed. The mean number of days between the first and second HoNOS-ABI score was 187.8 (SD: 262.3, range: 4 – 1209).

There was a significant drop in HoNOS-ABI scores over time from an overall mean of 13.9 (SD: 5.7) to 11.9 (SD: 6.2) (t =2.9, df = 53, p = 0.005). Data were stratified by gender, ethnicity, employment, health, and experiences of CSA. There was a significant drop in HoNOS-ABI scores for men only, both British and non-British patients, patients who did not experience CSA, patients who did not work as carers, those that worked in social or health care, and patients with a comorbid physical health problem. Table 41 outlines HoNOS-ABI scores for functional motor patients.

Table 41 First and last available HoNOS-ABI scores in functional motor disorder group

		First HoNOS-ABI adjusted score mean (SD)	Last HoNOS-ABI adjusted score mean (SD)	Mean diff	*t* test	*p* value
Functional motor group (n = 54)		13.9 (5.7)	11.9 (6.2)	1.99	2.9	**0.005**
Gender	Female (n = 43)	13.6 (5.7)	12.2 (6.2)	1.35	1.78	> 0.05
	Male (n =11)	15.2 (6.1)	10.7 (6.1)	4.5	3.34	**0.007**
Ethnicity	British (n = 37)	14.6 (5.7)	12.5 (6.2)	2.1	2.25	**0.03**
	Other ethnicity (n = 17)	12.5 (5.8)	10.8 (6)	1.76	2.22	**0.04**
CSA	Experienced CSA (n = 13)	14.3 (6.7)	11.6 (6.7)	2.7	1.4	> 0.05
	Didn't experience CSA (n = 35)	13.9 (5.5)	12.3 (6.2)	1.63	2.2	**0.04**
Health	Physical health problem (n = 43)	14 (5.8)	11.5 (6.4)	2.5	3.3	**0.002**
	No physical health problem (n = 8)	14.2 (6.1)	13.6 (5.3)	0.6	0.5	> 0.05

Range: 0 (best) - 48 (worst)
Only one control participant had two HoNOS-ABI scores so no control group analysis was conducted

5.3.5.3 PHQ-9 scores

In total, 20 FMD participants had two PHQ-9 scores. In groups populated by less than five patients, no comparisons were conducted. No PHQ-9 information was available on control group patients. The mean number of days between the first and last PHQ-9 score for functional motor patients was 162 days (SD: 195.3, range: 30 – 925).

FMD patients showed a statistically significant reduction in PHQ-9 scores over time from a mean of 14.3 (SD: 7.7) to a mean of 11.1 (SD: 6.6) (t = 2.6, df = 19, p = 0.02). Data were stratified by socio-demographic variables. Female, and British patients, those not working as carers, and those who did not experience CSA showed a significant improvement in scores over time. For all other groups, there was no significant change in PHQ-9 scores. See Table 42 for the first and last available PHQ-9 scores for FMD patients.

Table 42 First and last available PHQ-9 scores for functional motor disorder patients

		First available PHQ-9 mean (SD)	Last available PHQ-9 mean (SD)	Mean diff	*t* test	*p* value
Functional motor group (n = 20)		14.3 (7.7)	11.1 (6.6)	3.2	2.6	**0.02**
Gender	Female (n = 18)	13.6 (7.5)	10.7 (6.1)	2.8	2.2	**0.04**
	Male (n =2)	21 (7.1)	14.5 (13.4)	-	-	-
Ethnicity	British (n = 15)	15.5 (7.4)	11.9 (7.1)	3.7	2.4	**0.03**
	Other ethnicity (n = 5)	10.6 (8.2)	8.8 (5.1)	1.8	0.9	> 0.05
CSA	Experienced CSA (n = 3)	8 (3.5)	6.7 (2.5)	-	-	-
	Didn't experience CSA (n = 15)	16.9 (6.8)	12.7 (6.7)	4.1	2.7	**0.02**
Work	Employed (n =2)	16.5 (7.8)	14.5 (7.8)	-	-	-
	Unemployed (n =16)	14 (8.3)	11.1 (6.8)	2.9	2	> 0.05
	Works as carer (n = 4)	10.3 (11)	10 (10.2)	-		-
	Not a carer (n = 16)	15.3 (6.7)	11.4 (5.9)	3.9	2.7	**0.02**
	Patient is a social/health worker (n = 4)	16.5 (5)	14.5 (6.7)	-	-	**-**
	Patient not a social/health worker (n = 16)	13.8 (8.3)	10.3 (6.6)	3.5	1	> 0.05
Health	Physical health problem (n = 14)	12.6 (7.8)	10.4 (7.3)	2.2	1.6	> 0.05
	No physical health problem (n = 6)	18.3 (6.2)	12.8 (5)	5.5	2.4	> 0.05

Scoring guide: '0-4' no depression; '5-9' mild; '10-14' moderate; '15-19' moderately severe; '20-27' severe

Two participants had two HoNOS-ABI scores so no control group analysis was conducted

5.3.6 Logistic regression

Using a binary logistic regression model, characteristics differentiating FMD and control group patients were investigated. The regression model indicated that being female (OR: 2.04, p = 0.008), married (OR: 4.02, p = 0.001), employed pre-morbidly (OR: 2.08, p = 0.045), having a physical health condition (OR: 2, p = 0.02) and having a carer (OR: 2, p = 0.007) were associated with status as an FMD patient. Being British, a health or social care worker, smoker, having had a psychiatric inpatient admission, being a carer, and having experienced sexual or physical abuse in childhood or adulthood were not predictive of membership of the FMD group. The

Cox and Snell pseudo *R*-square was 0.21 indicating that the fit of the model to the data was poor. The model correctly predicted 51% of FMD patients and 82.4% of control group patients. Table 43 outlines the regression model.

Table 43 Logistic regression analysis of factors affecting membership of the functional motor disorder group

Independent variables	b	se	Wald	*p* value	OR	95% CI
Female	0.71	0.27	6.95	**0.008**	2.04	1.2 – 3.5
British	0.19	0.25	0.62	0.43	1.22	0.75 – 2
Married	1.4	0.28	25.3	**0.001**	4.02	2.3 – 6.9
Employed pre-morbidly	0.73	0.37	4	**0.045**	2.08	1 – 4.3
Health or social worker	0.24	0.36	0.46	0.50	1.28	0.6 – 2.6
Smoker	-0.28	0.25	1.26	0.26	0.76	0.5 – 1.2
Psychiatric inpatient stay	-0.28	0.24	1.3	0.25	0.76	0.5 – 1.2
Physical health problem	0.69	0.28	6.3	**0.01**	2.0	1.2 – 3.5
Carer to family or friend	0.76	0.58	1.73	0.19	2.15	0.69 – 6.7
Has a carer	0.69	0.26	7.24	**0.007**	2.0	1.2 – 3.3
Abuse experience*	0.29	0.17	3.03	0.08	1.3	0.96 – 1.9

Model $\chi 2 = 93.6$, $p < 0.001$
Pseudo $R^2 = 0.21$
n = 966

The dependent variable is membership of the functional motor disorder group coded as 0 = control group and 1 = functional motor disorder patient
*Abuse experience: collation of CSA, CPA and ASPA categories resulting in three point Likert scale (1-3)

5.3.7 Sensitivity analysis

Schizophrenia patients account for at least 23.1% of the control group in this study. One hypothesis is that the severity of a disorder like schizophrenia may account for some of the statistically significant differences seen between the FMD and control groups.

In order to explore this possibility further, any patient with a schizophrenia, schizotypal or delusional disorder diagnosis (F20 – F29) in either the FMD or control groups was removed and univariate analyses assessing socio-demographic associations were conducted.

With the removal of any patient with a schizophrenia diagnosis from either group, the total number of FMD patients was now 312 (removal of 3.1% of patients) while the control group total number was now 495 (removal of 23.1% of patients).

After their removal from the analysis, there remained a significantly higher proportion of female FMD patients ($\chi^2 = 31.6$, $p < 0.05$). The higher rate of British FMD participants disappeared but the control group still had a higher proportion of Irish participants ($\chi^2 = 8.2$, $p < 0.05$), and significantly fewer patients from 'any other ethnic background' ($\chi^2 = 4.6$, $p < 0.05$).

FMD patients were still more likely than control group patients to be married (χ^2 = 66.8, p <0.05). The significant difference in employment rates disappeared but FMD patients were still more likely to have been employed pre-morbidly (χ^2 = 9.4, p <0.05). Differences in smoking rates remained, with control group patients still more likely to smoke than functional patients (χ^2 = 21.8, p <0.05). With the removal of schizophrenia patients from the analysis, control patients were now more likely than FMD patients to have a relative with a mental health problem (χ^2 = 7.7, p <0.05). There remained no difference in the rates of abuse between groups.

Table 44 outlines the differences between functional motor and control groups after the removal of patients with a schizophrenia (F20-F29) diagnosis.

Table 44 Socio-demographic comparisons with removal of all cases of schizophrenia, schizotypal, delusional, and other non-mood psychotic disorders

		Functional motor disorder n (%)	Control group n (%)	χ^2	95% CI	*p* value
Gender	Female	232 (74.4)	271 (54.7)	31.6	12.8 – 26.2	**0.001**
	Male	80 (25.6)	224 (45.3)			
Ethnicity	British	194 (66.4)	284 (60.8)	2.6	-1.5 – 12.9	0.10
	Irish	2 (0.7)	20 (4.3)	8.2	1.2 – 5.9	**0.004**
	Any other white background	13 (4.5)	38 (8.1)	3.7	-0.2 – 7.1	0.054
	Any other mixed background	0 (0)	2 (0.4)	1.17	-0.9 – 1.5	0.28
	African, Caribbean & Black	40 (13.7)	79 (16.9)	1.4	-2.4 – 8.5	0.23
	African	13 (4.5)	36 (7.7)	3.04	-0.6 – 6.7	0.08
	Caribbean	13 (4.5)	19 (4.1)	0.07	-2.6 – 3.8	0.79
	Any other black background	14 (4.8)	24 (5.1)	0.03	-3.3 – 3.5	0.85
	Asian[2]	11 (3.8)	13 (2.8)	0.58	-1.7 – 4.2	0.45
	Indian	2 (0.7)	1 (0.2)	1.15	-0.6 – 2.3	0.28
	Pakistani	1 (0.3)	2 (0.4)	0.05	-1.5 – 1.2	0.82
	Bangladeshi	1 (0.3)	2 (0.4)	0.05	-1.5 – 1.2	0.82
	Chinese	1 (0.3)	1 (0.2)	0.08	-0.9 – 1.6	0.78
	Any other Asian background	6 (2.1)	7 (1.5)	0.38	-1.4 – 3.1	0.53
	Any other ethnic group	32 (11)	31 (6.6)	4.6	0.13 – 9	**0.03**
	Total	292 (100)	467 (100)			
	Not known	20 (6.4)	28 (5.7)			
Marital status	Married or civil partner	139 (47.3)	93 (19.5)	66.8	20.8 – 34.6	**0.001**
	Not married	155 (52.7)	385 (80.5)			
Work	Employed	72 (25)	90 (19.9)	2.7	-1.2 – 11.6	0.10
	Unemployed	216 (75)	363 (80.1)			
	Employed pre-morbidly	240 (87.9)	307 (78.7)	9.4	3.2 – 14.9	**0.002**
Health	Smoker	67 (38.1)	142 (61.5)	21.8	13.3 – 33	**0.001**
	Mean BMI[1]	28.6 (8.9)	25.98 (6.7)	1.9		0.06
	History of psychiatric admission	101 (32.4)	169 (34.1)	0.25	-5.2 – 8.5	0.61
	Complication at birth	38 (29.5)	28 (34.1)	0.5	-8.7 – 18.3	0.48
	Family mental health history	121 (51.9)	159 (64.4)	7.7	3.4 – 21.4	**0.006**
Life events	CSA	48 (19.6)	70 (23.5)	1.2	-3.4 – 11	0.27
	CPA	57 (23.2)	70 (23.6)	0.01	-7 – 7.7	0.91
	Adult physical or sexual abuse	67 (26.7)	71 (23.2)	0.91	-3.9 – 11	0.34

[1] Independent *t*-test

With the removal of all patients with a schizophrenia diagnosis, a binary logistic regression analysis was repeated to assess the variables that predict membership to the FMD group. The Cox & Snell R Square was 33.7% and the model correctly predicted 78.8% of cases. Some of the significant associations with FMD membership disappeared with the removal of the schizophrenia patients.

Variables that were no longer associated with FMD patients included gender, pre-morbid employment and having a carer. The variables that were significantly associated with FMD membership were being married (OR: 4.6, $p = 0.02$) and having a physical health problem (OR: 11.8, $p = 0.001$), see Table 102, ("Appendix 5.8: Logistic regression results").

5.4 Discussion

5.4.1 Main findings

This study identified 322 FMD patients from a database holding 250,000 patients' records. The associations between FMD and demographic, social, occupational, health and life events were investigated using a large number of control patients drawn from an extensive mental health case register (Stewart et al., 2009).

4.4.1.1 Socio-demographics

In our univariate analyses, FMD was associated with higher rates of female patients, British patients, private home ownership, employment, pre-morbid employment and employment in health and social care. FMD was associated with lower rates of Irish, African, Caribbean and black ethnicities, mortality, council tenancy occupancy, and the receipt of benefits.

The predominance of females in our study endorses existing evidence on the gender ratio of functional motor symptoms. The rate in this study of 73.9% is lower than the rate of 80% reported in Stone et al.'s (2009b) neurology outpatient study, the 79% reported by consultant neurologists in Scotland (Stone et al., 2010b), and the 78.8% in a neuropsychiatric inpatient unit (McCormack et al., 2014), but higher than the 60% reported in a neurology unit in a general hospital in Sweden (Binzer et al., 1997).

The gender difference may arise for a number of reasons. Women may be more likely to perceive and label a noxious sensation due to heightened body vigilance (Warner, 1995). Young women may be more likely to be socialised to communicate bodily distress (Mechanic, 1972), and women may be more likely to seek help for somatic symptoms (Nathanson, 1977). Other factors linked to gender may include genetic or personality predispositions (McCrae et al., 2000). This is discussed in greater detail in Chapter Seven.

Our study found a higher rate of British patients compared to the control group. Hysteria, historically, was conceptualised as a disorder which arose when cultural or ethnic groups did not hold sophisticated psychological models with which to understand emotional distress or explain common somatic symptoms (Kleinman, 1982; Lambo, 1956). The argument follows that as Freudian theories became more common in western culture, the incidence of hysteria reduced. The argument's subtext is that somatic complaints are an expression of emotional distress by less 'psychologically sophisticated' people who do not have the tools to express suffering or grief.

This reasoning is almost entirely discredited. The incidence of functional neurological symptoms in western culture has not reduced since Freud's exposition (Carson et al., 2000) and there is no evidence to suggest that certain ethnic groups or cultures have higher rates of FND or unexplained symptoms. A systematic review concluded that the lack of high-quality evidence from cross-cultural studies makes it difficult to draw firm conclusions on the cross-cultural variations of FND but that when FND does occur, its features are similar across countries (Brown & Lewis-Fernández, 2011). This suggests some degree of universality of the disorder. In addition, the argument that 'psychologically unsophisticated' patients are more likely to present with somatic symptoms is spurious given the epidemiological evidence that patients with functional somatic symptoms also report high rates of psychological symptoms (Katon et al., 1991).

The ethnic profile of our control group is very similar to the profile of all SLaM patients in the CRIS records. Perera et al., (2016) reported that 50% of active CRIS patients were British. The statistical difference in British ethnicity is likely partly explained by the ethnic profile of schizophrenia patients in our control group, supported by previous research which highlights the link between high rates of psychosis in the Black Caribbean population (Fearon et al., 2006). Our sensitivity analysis shows that with the removal of schizophrenia patients, the statistical difference in British ethnicity rates disappears. From our study, the evidence suggests that within SLaM, a London-based Trust with a culturally diverse metropolitan population, FMD is no more common a mental health diagnosis amongst certain ethnicities than other disorders.

Previous evidence suggests a link between lower socio-economic status (SES) and FND (Binzer et al., 1997; Stefansson et al., 1976). Commonly used indicators of SES in health research includes education, income, wealth (Galobardes et al., 2007) and parental education (Erola et al., 2016). None of these variables were routinely available in CRIS so a robust SES measure was not included. Potential proxies of SES in our results include marital status, housing and employment, the findings of which contradict the suggestion that FMD is related to lower SES.

In our study, FMD patients are more likely to be married (both male and females), more likely to live in privately owned homes, more likely to be employed, and less likely to receive benefits than control patients. Of patients in the study who were actively employed or had a history of employment, significantly fewer FMD patients worked in elementary occupations which required fewer skills. While marital status, housing and occupation are likely collinear factors, together, they may indicate a higher SES status. Again, our results will be influenced by our comparator group whose SES status may artificially inflate the results observed in our FMD group.

The rate of employment in care-giving positions within health and social care amongst FMD patients is worth highlighting. Previous evidence in this area is conflicting. Recent results from a movement disorders clinic found no difference in the proportion of healthcare workers between FMD and control patients (although the rate was elevated in the functional group at 25% versus 20%) (Perry et al., 2017) and no difference in rates were observed between patients with essential and psychogenic tremor (Kenney et al., 2007). McCormack et al. (2014) observed that 45.5% of FMD patients had previously been employed as health or social care workers, significantly higher than the rate observed in their control group.

Office for National Statistics data in 2001 reported that healthcare workers accounted for 6% of the UK's economy; and four-fifths of these workers were women (Yar et al., 2006). 19% of FMD patients in our study had worked or currently worked in health or social care jobs compared to 8.2% in the control group. The difference between groups may partly be explained by underemployment in the control group or the higher prevalence of females in our FMD group. When health and social care work was stratified by gender, the difference was maintained only in women. In our logistic regression analysis, health and social care work was not associated with an FMD diagnosis, likely because gender was accounted for.

Nonetheless, a reasonable proportion of FMD patients worked in care-giving employment, 10% of FMD patients were carers to family members or friends, and 40% had a carer themselves. A common theoretical argument is that working in healthcare roles or observing a family member with a neurological disease allows a person to model neurological symptoms (Shill & Gerber, 2006). It is possible that there is something particular about the social act of giving care that precipitates or moderates the development of functional neurological symptoms, for example through burnout, low pay or insecure employment. Alternatively, a confounding factor like personality, not assessed in our regression analysis, might independently predispose patients to an FND diagnosis and to work as carers.

5.4.1.2 Health

A range of functional motor symptoms were observed with weakness the most common type. Weakness was also the most common symptom reported in FND patients admitted to an acute stroke ward (Gargalas et al., 2015). In movement disorders clinics, tremor is more commonly found to be the most prevalent functional symptom (Factor et al., 1995; Hinson & Haren, 2006), but service referral patterns likely explain this finding. Most FMD patients had more than one symptom. Caution is necessary when interpreting our results as symptoms were categorised after collection from the medical records and it is possible that some observer bias was involved in the construction of symptom categories.

Over half of the FMD group (58.2%) had used, or currently used a wheelchair, Zimmer frame or a walking stick. This is lower than the rate of 84.8% in patients with FMD admitted to a neuropsychiatry unit (McCormack et al., 2014). Patients in McCormack et al.'s study were more likely to more severe or entrenched symptoms given their inpatient admission. This is supported in our study where of the FMD patients who had received an inpatient admission, 76.3% used a walking aid while 23% did not. Our rate of 58.2% is likely to be an underestimate given that no information on mobility aid status was available in 35% of patients' records.

FMD patients were less likely to be current smokers compared to control cases. Unexpectedly, the significant smoking rate difference was not explained by the presence of schizophrenia patients in the control group. Patients with mental health disorders generally however have consistently high rates of smoking compared to the general population (Dierker & Donny, 2008; Lê Cook et al., 2014) and smoking may, at least partially, account for their higher mortality compared to the general public. In this case, smoking may be a form of symptom control and reduce anxiety.

Our finding suggests that FMD is a protective factor against smoking compared to the control group but FMD patients in our study were still more likely to smoke than the English general public. This was relatively surprising as it was hypothesised that patients with an FMD diagnosis might be more health-conscious or health-anxious and, as a result, be less likely to smoke than the general public. There is however little previous research on smoking in FMD or other somatoform disorders. A survey of general practice found no difference in current smoking rates between patients with persistent medically unexplained symptoms and patients with medical diagnoses (Dirkzwager & Verhaak, 2007). Our logistic regression analysis did not find any relationship between smoking and FMD membership. It is likely that pre-morbid employment, a history of health or social care work and a psychiatric admission history partly mediate or confound the relationship between smoking and FMD membership.

No differences were observed on BMI scores between our FMD and control groups, however FMD males had a significantly higher mean score than male controls. Firm conclusions cannot be drawn as BMI data was not consistently available. It is possible that BMI was recorded by a clinician when weight was treated or seen as specifically problematic. Our study collected the latest available data on BMI so it is also possible our results are an underestimate as patients' scores may improve once in the healthcare system as a general response to healthcare, or to specific weight management treatment.

74.5% of FMD patients had a comorbid physical health condition and they were nearly twice as likely to experience illness compared to the control group. The most common type of illness was neurological of which headache was the most common example. FMD patients were less likely to have infectious and parasitic diseases, a result which may be explained by the higher occurrence of HIV and hepatitis amongst substance abuse patients in our control group.

That FMD patients experience more neurological comorbidities is not unexpected. NES patients report more migraine than patients with epilepsy (Shepard et al., 2016). Neurological disease comorbidity has been reported in 12-17% of FMD patients (Feinstein et al., 2001; Kim et al., 1999). In these studies, comorbid disease was most frequently organic tremor and Parkinson's disease. The high rate of physical health co-morbidities found in our FMD group may be somewhat inflated however due to our classification of headache as a neurological disease rather than as a comorbid functional disorder. A further analysis which reclassified headache as a functional disorder would likely reduce the rate of comorbid illness in FMD patients. Future research might benefit in distinguishing headache from migraine and classifying them as two separate entities.

These results might be influenced by a referral or surveillance bias. In order to qualify for inclusion in our study, FMD patients will have been referred to a physician prior to their FMD diagnosis. Attending a doctor's appointment will mean you are more likely to detect an existing illness compared to control patients who may be less likely to have their physical health monitored. In addition, a clinician might be more likely to look for, and subsequently find, physical health issues as they may be concerned about potentially misdiagnosing a functional patient. There is some evidence of this in our study as the 'unknown' rate of physical diagnoses was higher in the control group than the FMD group indicating that the issue of physical health was not being brought up in control group participants' psychiatric consultations.

5.4.1.3 Life events

No associations were found regarding rates of childhood sexual or physical abuse or adulthood sexual or physical abuse and FND diagnosis.

The 20% rate of CSA in our study was slightly lower than previous reported rates in FND. Rates range from 24% (Roelofs et al., 2002), 25% in an all-female sample (Akyuz et al., 2017) to 26.3% (Sar et al., 2004). These studies recruited from psychiatric settings and used a broad definition of functional disorder.

Our 22.7% rate of CPA corresponds to the rate in Nicholson et al.'s (2016) study of 23.2%, and the 23.8% rate reported in patients with conversion disorder in public hospitals in Lahore (Farooq & Yousaf, 2016), but is lower than the 27.3% reported by McCormack et al. (2013) in an inpatient setting, and the 28% reported by Roelofs (2002) in psychiatric settings. In psychiatric outpatient settings in Turkey, physical abuse has been reported to be as high as 44.7% (Sar et al., 2004) and 53% (Akyuz et al., 2017), both in psychiatric outpatient settings in Turkey. These higher rates may reflect cultural differences and the high proportion of women in study samples.

The finding in our study that childhood abuse rates did not differ between the FMD and control group may be surprising given the theoretical antecedents of FND. Nonetheless, it is well established that there is a link between sexual abuse and many other later life mental health disorders, for example the association between the experience of CSA and psychosis is well-established (Bebbington et al., 2011) and a meta-analysis reported a history of sexual abuse was associated with an increased risk of anxiety, depression, eating disorders, posttraumatic stress disorder, sleep disorders, and suicide attempts (Chen et al., 2010). These associations persist, regardless of gender or the age at which abuse begins. It is therefore likely that abuse will feature to some degree in a proportion of all mental health diagnoses. We are likely to have observed a statistical difference had we compared FMD patients to health controls.

It is important to note the assessments used to measure prevalence of abuse. Many previous studies used semi-structured clinician-led interviews such as the Structured Trauma Interview (Akyuz et al., 2017) and the Life Events and Difficulty Schedule (Nicholson et al., 2016). The result in our study may underestimate the true rate given our retrospective design and our necessary reliance on clinicians' data. Memory of past experiences is dependent on cognitive ability and shaped by subsequent re-tellings. Patients with mood disorders may be systematically more or less likely to report abuse, something we were unable to control for.

Eliciting information on abusive or traumatic experiences requires skilled training and a considerable amount of clinical time, a factor we could not assess in our results.

In addition, we were limited in the type of information we could collect. The type of abuse, the length of time it persisted, who the abuser was in relation to the victim, and the age of abuse onset may all contribute to the emergence of FMD. Due to the limitations of using a retrospective clinical database, we did not include a severity index in our study or assess the experience of specific types of abuse. A patient who experienced sexual abuse once will be categorised in the same way as a patient who was chronically abused throughout their childhood, likely obscuring some of the nuances in the link between exposure to abuse and FMD manifestation. In addition, the lack of specific information on abuse means we are unable investigate possible causal processes involved.

The qualitative analysis in our study of life events showed an increase in negative events prior to symptom onset. FMD patients were more likely to have been bullied in primary or secondary school, to be involved in workplace, school or university disputes, legal disputes, and to experience problems in a sexual relationship like divorce or interpersonal violence. Taken together, these events could be defined as difficulties within interpersonal relationships; a finding somewhat echoed by Stone et al. (2004) who note that patients with pseudoseizures had a higher rate of life events linked to family life than patients with motor symptoms.

Regarding personality, dependent personality disorder and histrionic personality disorder have been reported to feature in between 10-20% of FND cases (Toone, 1990). This finding is not borne out in our diagnostic results as only 7.8% of the FMD sample had a secondary comorbid personality disorder diagnosis. It is possible that clinicians are reluctant to give a definitive personality diagnosis. In addition, our study did not include any validated personality assessment. Firm conclusions on the role personality play in FMD cannot be made.

5.4.1.4 Regression analysis

Our logistic regression analysis found the independent variables associated with an FMD diagnosis were female gender, being married, having pre-morbid employment, having a comorbid physical health problem, and having a carer. Part of these associations may be explained by the make-up of the control group. When patients with a schizophrenia diagnosis were removed from both the control and FMD group, the only predicative independent variables of FMD membership were being married, and having a physical health condition.

5.4.1.5 Outcome measures

The first and last available HoNOS, HoNOS-ABI and PHQ-9 scores were collected. Two HoNOS scores were available for 21.4% of the FMD group, but 49.7% of the control group. FMD patients' HoNOS scores remained stable over time but were not significantly different to the control group, who did see improvements in scores over time. FMD patients' HoNOS-ABI and PHQ-9 significantly improved with time.

Previous research suggests prognosis of FND is poor. A systematic review by Gelauff and Stone (2016) reported that 40% of patients were the same or worse at follow-up while 20% of patients showed a complete remission. The primary purpose of our study was not to assess prognosis. It is also difficult to draw definitive conclusions on patient improvement given the low percentage of available clinical information on FMD patients and the fact that the clinical scores relate only to time and not to a specific psychosocial intervention or medication. Our sample was drawn from across the Trust and different patients may have been given different types of treatment or no intervention at all, information that was not available to assess. The reduction in scores might equally be explained by a regression to the mean phenomenon. The following chapter examines scores linked to a CBT intervention and allows for a more robust interpretation of clinical improvement.

A future study might find it beneficial to examine the clinical sub-scales which could help draw out the associations between specific psychological factors and socio-demographic variables, symptoms and clinical correlates.

5.4.2 Strengths and limitations

This study is one of the largest on FMD in the field and benefits from access to a range of rich clinical data.

The method we employed to identify cases relied on a keyword search. This allowed for the establishment of a large case series of patients with a confirmed diagnosis of FMD. Our search strategy however did not allow us to assess the false negative rate and it is likely that there were patients in the CRIS database who did not appear in our search, but who nonetheless had an FMD diagnosis. Given the multitude of synonyms associated with a functional disorder diagnosis, it is possible that our search terms were not exhaustive and more FMD patients were present in the database than were detected in our study. While the search strategy we employed allowed for the collection of a large amount of data, it does not allow us to calculate the overall FMD prevalence rate in SLaM.

A second limitation relates to the specialised nature of SLaM services and possible limitations on generalisability. SLaM provides a tertiary neuropsychiatry service through the Lishman Unit and a neuropsychiatry outpatient service who receive referrals from across the UK. Our FMD patients may be more severe than patients observed in other Trusts. While this may affect the generalisability of our findings, it is unlikely to affect our comparative analyses as SLaM also provides many tertiary services which also offer national referrals. These services are represented in our control group, for example the Behavioural Genetics Service, the maternal and perinatal mental health services, and Attention Deficit and Hyperactivity disorder (ADHD) services. Our case-control design ensures that the selection factors and biases that lead to a patient receiving treatment from secondary and tertiary mental healthcare services are accounted for in our analyses and it is the factors that are most specific to FMD that we sought to highlight.

Another potential difficulty linked to the referral issue is that this study will only represent patients who have receive a referral to clinical services at all. There may be FMD patients who are less likely to receive a referral to secondary or tertiary services and such patients may be systematically different to those we have observed in this study. For example they may have more severe symptoms or be demographically different in certain ways. Such a bias is inherent in much healthcare research where those patients who receive referrals and treatment are likely to be different to those who do not.

The data in this study was obtained from clinicians' notes. Any clerical errors will therefore be reproduced in our study. Clinicians' own biases or fluctuating trends in clinical formulation or case note writing may affect results. An example of this would be a theoretical presumption on the link between bullying and FMD. A clinician who believes a link exists may be more likely to ask about bullying experiences or to record it compared to a clinician making other causal assumptions. These types of biases may be mitigated due to our study's large sample size and the broad range of services included in the study.

A 'not known' and 'not applicable' category was included when appropriate throughout our study to allow for the estimation of missing data. This allowed for the recording of instances where no information on a variable was available. In the case of childhood sexual and physical abuse, rates of 'unknown' information were higher in the control group, perhaps suggesting clinicians were not as likely to routinely address abuse experiences compared to FND consultations. A related issue concerns researcher bias. Data in this study could not be collected blind and it is possible the researcher's own biases may have affected data collection.

A further limitation relates to information regarding life events. Assessing potential life experience precipitants highlighted associations between FMD and certain life events like bullying or difficulties in the workplace. There is a potential difficulty however as the categorical nature of the data could not account for the severity or duration of these events. Two separate experiences of bullying or abuse may represent very different phenomenological experiences as patients will assign different meaning and narratives to experiences Our results regarding these precipitants should be viewed as preliminary and our life event results should not be viewed as having predictive power. Future research in this area may benefit from the employment of vignettes and standardised face-to-face interviewing to allow for subjective experience and personally ascribed meaning to be taken into account.

5.4.3 Conclusions

This study is one of the largest studies on FMD. It draws on a large medical database which allows for the exploration of a broad range of clinical, demographic and health factors. This is an exploratory study and its results suggest there are specific and distinctive features of functional motor disorder.

Chapter Six: A case-control study assessing outcomes of functional motor disorder patients receiving outpatient cognitive behavioural therapy in South London and the Maudsley

6.1 Introduction

Chapter Five described an exploratory study investigating the demographic, social, and health factors associated with the presentation of FMD in South London and the Maudsley (SLaM) NHS Trust. This chapter investigates the outcomes of patients with the same disorder who received outpatient CBT from a neuropsychiatric clinic in SLaM.

The neuropsychiatry clinic treats patients with psychological complications resulting from neurological disorders such as epilepsy, Tourette's syndrome, movement disorders, and dementia. The clinic also receives referrals for patients with depersonalisation, functional, somatoform, and other dissociative disorders.

This introduction discusses the cognitive-behavioural model of therapy, evidence for CBT treatment of somatoform disorders generally and functional disorders specifically, the types of assessments used to assess clinical change, and outlines the aims of this study.

6.1.1 The cognitive-behavioural model

CBT is a talking therapy that emphasises the importance of cognitions and behaviours in the maintenance of mental disorder and distress.

In early iterations of the CBT model, Beck (1970) and Ellis (1962) argued that maladaptive cognitions contribute to the maintenance of emotional distress and behavioural problems. These cognitions include general beliefs and schemas about the world, the self, and the future, which can give rise to specific and automatic thoughts about situations, and which may lead to maladaptive behaviour. The CBT model makes three assumptions: i) cognitive activity affects behaviour, ii) cognitive activity can be monitored and altered by the self, and iii) changing peoples' cognitions can change behaviour (Dobson & Dozois, 2010).

The goal of CBT is the reduction of symptoms and the improvement of functioning. Treatment is viewed as a collaborative exercise in problem-solving where maladaptive cognitions are challenged and changed in order to modify behaviours (Hofmann et al., 2012). CBT draws from the "three P" model which distinguishes causal factors as predisposing, precipitating and perpetuating in the development of distressing symptoms (Beck, 1976).

Predisposing factors are those relatively early risk factors such as genetics, birth or developmental processes. As outlined in Chapter Five, there is some evidence on the occurrence of traumatic life events and the development of functional disorders. Such events

include witnessing parental illness as a child (Walker et al. 1993), childhood adversity, parental neglect and childhood physical and sexual abuse (Alper, 1993; Fiszman et al., 2004; Kaplan et al., 2013; Karatzias et al., 2017; Leroi et al., 1995; Morrison, 1989; Roelofs & Spinhoven, 2007; Walker et al., 1997; Walker et al., 1993; Wing et al., 1998). The evidence suggests a dose-response relationship between trauma and functional disorder symptoms (Karatzias et al., 2017) where specific types of events may have stronger associations than others such as the death of a partner or parent, and life threatening illnesses or injury.

Precipitating factors may occur close to the onset of symptoms for example the loss of a job, the onset of a physical disease, financial or social distress like the breakdown of a relationship. Known factors in the precipitation of unexplained symptoms include physical assault, domestic violence (Koss et al., 1991), trauma (Solomon, 1988), and natural disasters (Escobar et al., 1992). These experiences may interact with predisposing factors and push the patient into a distressed state.

The timing of the event may be important. Nicholson et al. (2016) found FMD patients were more likely to have experienced a severe life event in the month prior to symptom onset compared to patients with depression and healthy controls. These events were also more likely to be, 'escape events', defined as events that could be changed or affected by becoming unwell. Examples include unpleasant work environments or relationship difficulties, where becoming unwell could help a person escape an unpleasant experience (Aybek et al., 2014). Unlike the often inconspicuous onset of a disorder like depression or anxiety, Stone et al. (2012b) argue that functional symptoms often start acutely and may be an active responses to life events.

Perpetuating factors are those that prolong the symptom experience. These factors range from social isolation (Lidbeck, 1997) to personal factors like attention (Barsky et al., 1988), bodily arousal (Heim et al., 1998), illness beliefs (Kolk et al., 2003; Sensky, 1997), and illness behaviour (Allen et al., 2006). Perpetuating factors are often the first to be addressed in CBT sessions.

No unified causal model explains why some people develop functional motor symptoms and others do not. Each patient may have causes that are specific to them alone. CBT's theoretical model identifies cognitive, behavioural, affective and physiological factors focusing on the issues linked to the perpetuation of symptoms. There is an underlying assumption that no single process or cause explains symptoms but rather a multi-factorial interaction these factors drives symptom expression (Deary et al. 2007).

One approach that reflects the multi-factorial nature of CBT is the 'five areas assessment' (Williams, 2001) highlighted in Figure 33 below. The person's social situation, symptoms, behaviour, thoughts, and emotions are appraised, and the causal explanations that a patient makes regarding their symptoms are viewed as highly relevant.

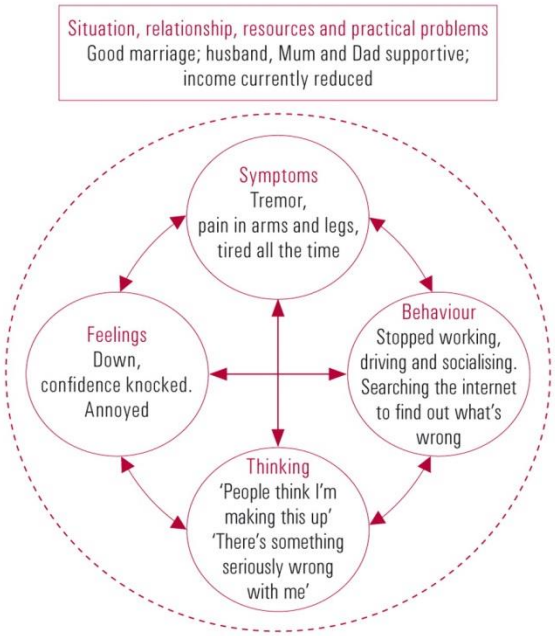

Figure 33 The five areas assessment model (reproduced courtesy of Kent and McMillan (2009))

In treating FND, a CBT therapist adopts a number of techniques to address perpetuating and precipitating factors. Techniques include muscle relaxation, psychoeducation, grounding techniques to address anxiety, challenging misinterpretations of physical symptoms, teaching problem solving skills in daily life, facilitation of emotional awareness, cognitive restructuring of dysfunctional thoughts and illness beliefs, and helping to improve interpersonal communication. Thought diaries are often used where patients list symptoms along with accompanying feelings and thoughts (Sharpe et al., 1992). These techniques are often employed in order to identify and restructure maladaptive cognitions and to alter illness behaviour.

Patient engagement is an important part of the CBT process, and may be particularly difficult for FMD patients as they may be invested in finding a medical explanation for symptoms. Clinicians will often begin by eliciting patients' conceptualisations of their own symptoms. It is advised that all medical investigations are completed by the time the patient starts therapy to remove any doubt about symptom cause although the possibility of a physical diagnosis can never be definitively ruled out (Kent & McMillan, 2009). This is not necessarily an impediment to therapy as one of the therapy goals for FND patients is to help them adopt a more

integrated view of their symptoms, one that highlights the interaction between physical and psychological processes.

In summary, CBT attempts to help patients become aware of, and to examine the way they think, respond emotionally, and behave in response to their unexplained symptoms. While the overall aim is often to increase functioning and reduce symptoms through the reinterpretation of bodily symptoms, changing illness cognitions, beliefs, and avoidant behaviour are an important part of the CBT process.

6.1.2 Existing evidence for CBT

This section outlines evidence on the effectiveness of CBT for somatoform disorders generally and functional disorders specifically.

6.1.2.1 Somatoform disorders

There is good evidence that CBT is effective in the treatment of most somatoform disorders.

A meta-analysis included sixteen studies which trialled the effects of psychotherapy for severe somatoform disorder (Koelen et al., 2014). The effect of psychotherapy on physical symptoms (Cohen's *d* = 0.80) and psychological symptoms (Cohen's *d* = 0.75) was large and these improvements were maintained nearly a year after treatment. Younger people, women, and patients with somatization disorder showed greatest improvements.

A systematic review comprising fifteen randomised controlled trials (RCTs) examined the effects of CBT on CFS (Price et al., 2008). Fatigue mean scores at post-treatment significantly reduced with 40% of participants showing a clinically significant response to treatment compared with 26% in usual care.

Another review of CBT distinguished between trials targeting specific syndromes such as CFS, IBS and pain (25 studies) and those focussing on general somatisation (6 studies) (Kroenke & Swindle, 2000). The most frequent primary outcomes in these studies were reductions in physical symptoms, followed by reductions in psychological distress and improvements in functional status. Across all studies, physical symptoms were most responsive to treatment compared to control conditions.

Nezu et al. (2001) completed a systematic review on the effects of treatments on medically unexplained symptoms. CBT resulted in improvements in physical and social functioning. Looper and Krimayer (2002) also found evidence on the efficacy of CBT in the treatment of medically unexplained syndromes and these authors argue that CBT should be the first line of

treatment offered for these patients but that a minimum duration of treatment has yet to be established.

A Cochrane review evaluated psychological therapy and its effects on somatoform disorders and patients with medically unexplained physical symptoms (van Dessel et al., 2015). Fourteen of the 21 studies were CBT studies. They found CBT was more effective than usual care in reducing the severity of symptoms and this remained at follow-up. Studies with the lowest effect sizes also offered the lowest intensity CBT. Overall, CBT had the same proportion of dropouts as usual care. The authors suggest that psychological therapies are better than standard care but, effect sizes are small.

Regarding specific somatoform diagnoses, of six trials examining the effect of CBT on back pain, symptoms improved significantly in four (Turner, 1982; Nicholas et al., 1991; Turner & Jensen, 1993; Lamb et al., 2010). However, depressive symptoms improved in only one trial (Turner, 1982). The number of CBT sessions offered across these studies tended to be small ranging from five to eight.

There is evidence that CBT is effective in the treatment of CFS. A systematic review (Whiting et al., 2001) reported an overall positive effect of CBT in three of four RCTs (Deale et al., 1997; Prins et al., 2001; Sharpe et al., 1996). One of the trials followed patients for five years post-intervention and global improvement was sustained as well as the proportion of patients who had recovered completely (Deale et al., 2001).

CBT is effective in the treatment of IBS. A meta-analysis assessed the results of eighteen RCTs (Li et al., 2014) and CBT was superior in reducing the number of symptoms compared to waiting lists, medical intervention controls, and basic support groups. A recent meta-analysis found psychological therapies, of which CBT treatment was the most frequent, produced a greater average improvement in mental health and daily functioning compared to control interventions, but no significant effects emerged for the number of sessions or the duration of therapy (Laird et al., 2017).

A small trial examined the effect of CBT for patients with medically unexplained physical symptoms and compared it to optimised medical care (Speckens et al., 1995). This study acknowledged the heterogeneous nature of patients' symptoms and adopted a broad CBT approach. While the authors didn't specify a primary outcome measure, they did report a higher recovery in the intervention group along with a lower intensity of physical symptoms. Another study comparing eight sessions of CBT to a waiting list control found reductions in physical symptoms and hypochondriacal beliefs (Lidbeck, 1997). A large RCT tested 10-weekly

CBT sessions compared to usual care for patients with multiple unexplained somatic symptoms (Allen et al., 2006). Symptoms were significantly less severe in those after receipt of CBT and there was a greater decrease in health care costs.

These findings suggest psychotherapy generally and CBT in particular are effective in the treatment of a range of unexplained symptoms although the evidence on the number of CBT sessions needed is not definitive. There is considerable heterogeneity in the follow-up lengths employed across studies and the outcome measures chosen. Most commonly, symptom reduction is the primary outcome in studies although this may not necessarily be the primary focus of CBT.

The following section examines the evidence for FNDs specifically.

6.1.2.2 Functional neurological disorders

There is evidence on the efficacy of CBT for functional neurological symptoms. CBT has been trialled in the treatment of NESs but less evidence exists on its effectiveness for patients with motor symptoms (Halligan et al., 2001).

La France et al. (2009) conducted a small non-controlled trial with 17 patients with NES. The CBT therapist in this study encouraged patients to make connections between their mood, cognition and environment as well as recognising automatic and catastrophic thinking, and misinterpretations of normal bodily sensations. Eleven of the 17 patients saw a 50% drop in their seizure attacks and anxiety, depression, quality of life, and psychosocial functioning improved.

In an RCT assessing the efficacy of CBT for NES, participants received standard neuropsychiatric care or standard neuropsychiatric care and one-on-one CBT (Goldstein et al., 2010). Twelve CBT sessions were offered with the primary aim of interrupting behavioural, physiological and emotional patterns at the start of a seizure. Participants in the intervention group reported a greater reduction NES than the control group although the difference was only slightly significant at a six-month follow-up period.

Sharpe et al. (2011) conducted a large RCT testing a CBT-based guided self-help workbook for patients with functional symptoms recruited from neurology services. This was compared to usual care. This sample included, but was not exclusive to, patients with functional motor symptoms. A number of limited face-to-face sessions were offered to explain the workbook and gave support where needed. At three months, 30% of intervention patients rated themselves better or much better compared with 13% of control patients.

There is limited evidence for CBT for functional motor disorder specifically. LaFrance and Friedman (2009) reported a case of a 22-year-old patient with functional generalised dystonia and facial twitching. By session four she had a complete resolution of her abdominal and arm dystonia. Her facial twitching improved intermittently but by week twelve, the authors report a complete remission.

Psychodynamic psychotherapy has been trialled for FMD patients with mixed results. Hinson et al. (2006) conducted a trial where ten patients received twelve weeks of psychodynamic psychotherapy, and antidepressants when necessary. Nine of ten patients showed an improvement in motor symptoms on a video rating scale. The same therapy was trialled by Kompoliti et al. (2014) over a six-month period. They found benefits for psychotherapy compared to observation and support. The small sample sizes of these studies make definitive conclusions are difficult to draw.

Given the high prevalence of functional disorders generally and the ubiquity of CBT as a treatment option in most mental health trusts, there is a surprising lack of information on CBT's effectiveness in treating FMD.

Unlike anxiety disorders or depression, the treatment of FMD with psychological therapies presents unique challenges. The continual revision in its case definition, the tendency for patients to be relayed between physical and mental health clinicians and the high rate of comorbid physical disease in this patient group may have contributed to a dearth of evidence in this area. It is likely that most patients are treated in primary care settings alone and many may never be offered or even accept psychological therapy.

Acceptability of CBT is a critical issue. Many of the studies outlined above do not report pre-treatment up-take rates or dropout rates once therapy starts. It is likely that patients who do not accept a psychosocial account of their symptoms will not be willing to take part in therapy. Problematically, many of the primary outcomes in these trials are reduction in somatic symptoms, but they do not address the psychological effects of the treatment. Our study attempted to address these concerns and address the general paucity of existing evidence on the effect of CBT on FMD.

6.1.3 Aim of study

This study utilised the CRIS medical record database used in Chapter Five to evaluate the outcomes of patients with FMD receiving CBT in an outpatient neuropsychiatry clinic in SLaM NHS Trust.

The socio-demographic and health characteristics of FMD patients were compared to a group of patients with organic symptoms who also received CBT at the same clinic in order to examine the potential risk factors for poor outcomes. Organic disease patients were chosen as the comparison group as they were less likely to have functional comorbidities and were therefore more likely to allow the identification of risk factors in FMD patients. We also sought to compare CBT-uptake and dropout rates, the rate of physical symptom improvements in FMD patients and the change in acceptance of psychological explanations amongst FMD patients between the start and end of therapy, and patients' clinical outcomes.

6.2 Methods

6.2.1 Study setting

The study sample was derived from the SLaM Biomedical Research Centre's (BRC) retrospective case register. A detailed description of CRIS and the SLaM trust is outlined in Chapter Five.

The neuropsychiatry service in SLaM provides neuropsychiatry inpatient and outpatient services in the form of assessment and treatment, neuroimaging, telemetry services, speech and language therapy, support and education for families and carers, and cognitive rehabilitation. Neuropsychiatric CBT assessment and treatment is provided by the clinic in the form of both inpatient and outpatient services.

If a patient is referred to the outpatient neuropsychiatry clinic, they are assessed by a neuropsychiatrist who takes a clinical history, completes a physical examination, and makes a formal assessment of the patient's mental state. They may also conduct a neuropsychological exam and complete neuroimaging and neurophysiological assessments.

If recommended by the consultant neuropsychiatrist, the patient may be referred for an outpatient CBT assessment.

6.2.2 The CBT intervention

The neuropsychiatric CBT team is made up of four CBT specialist practitioners. They offer two-hour assessments for patients who may have psychological, emotional, behavioural or psychosocial problems. Following assessment, they may offer patients a course of CBT. Treatment sessions are one hour. The normal course of treatment is 15 sessions which usually occur weekly but patients can be offered a longer course of treatment.

CBT sessions can include psycho-education, cognitive and behavioural techniques, and relapse prevention strategies. The therapist may challenge cognitive distortions that affect motivation and a patient's ability to engage on an interpersonal level. They will attempt to build a patient's insight so they can learn to accept a psychological understanding of their symptoms and teach methods by which the patient's locus of control shifts from an external to internal model. The patient may be encouraged to link their past and present experiences with their physical symptoms but this is not always the case. Other techniques include keeping mood and thought diaries where the patient links their mood and thoughts to their environment. These diaries may be used as homework material for the following week's session. Other activities include using relaxation techniques when a patient has fears and expectations around improvement and graded exposure techniques where they attempt to reduce avoidance.

6.2.3 Data collection

The aim of this study was to obtain detailed demographic, clinical, and treatment-related data for all patients with functional motor disorder treated with CBT in the neuropsychiatry outpatient clinic. This is a retrospective treatment outcome study with FMD cases and a clinical comparison group.

6.2.3.1 Ethics approval

CRIS was approved as an anonymised data resource for secondary analysis by Oxfordshire Research Ethics Committee (08/H0606/71+5). All CRIS projects are reviewed and approved by a dedicated patient-led oversight committee (Fernandes et al., 2013).

6.2.3.2 Inclusion and exclusion criteria

The study's inclusion criteria were as follows:

I. Aged over-18;

II. Patients received CBT treatment due to an ICD-10 diagnosis, 'Conversion disorder with motor symptom or deficit' (F44.4) or received treatment as a result of functional motor or movement symptoms (without a formal ICD-10 diagnosis stated in CRIS's structured text).

Inclusion criteria for control group participants were as follow:

I. Participants were included if they were aged over-18; and

II. Had a physical diagnosis with no evidence of functional symptoms and had received CBT treatment from the same neuropsychiatry clinic.

The study's exclusion criteria were as follows:

I. Any participants treated only for NESs;

II. A patient who was referred for treatment but treatment had not started;

III. Patients who had received only a CBT assessment and were awaiting treatment or referral to the clinic. Participants were however included if CBT treatment had begun but was not yet complete.

Twenty participants were included in this study whose treatment was on-going (nine cases and eleven controls). Controls were unmatched for demographic or clinical variables to allow for the assessment of between-group differences according to these variables.

6.2.3.3 Search strategy

The names of the four CBT clinicians working within CBT neuropsychiatry clinic were used as search terms on the CRIS interface to identify participants. CRIS returns patient level data if the clinician's name appears in the patient's clinical records at any stage. Table 45 outlines the numbers of patients returned with each clinician search in CRIS.

Table 45 Total service users returned in number of CRIS search linked to each clinical psychologist

	n (%)
Clinician one	29 (3.1)
Clinician two	215 (22.8)
Clinician three	291 (30.9)
Clinician four	406 (43.1)
Total	941 (100)
Duplicate cases removed	590

In total, 1531 patients were returned from the search. 590 (38.5%) were duplicates and were removed, leaving 941 unique service users.

Of these 941 patients, 573 patients were removed from our analysis. These patients had functional symptoms which were not classified as functional motor symptoms. The majority of these symptoms comprised NESs. Twenty-one patients were removed because they did not fulfil study criteria, for instance they were aged under-18. This left 200 patients with functional motor symptoms and 147 control patients.

Figure 34 outlines the flowchart showing the number of patients considered for inclusion in the study.

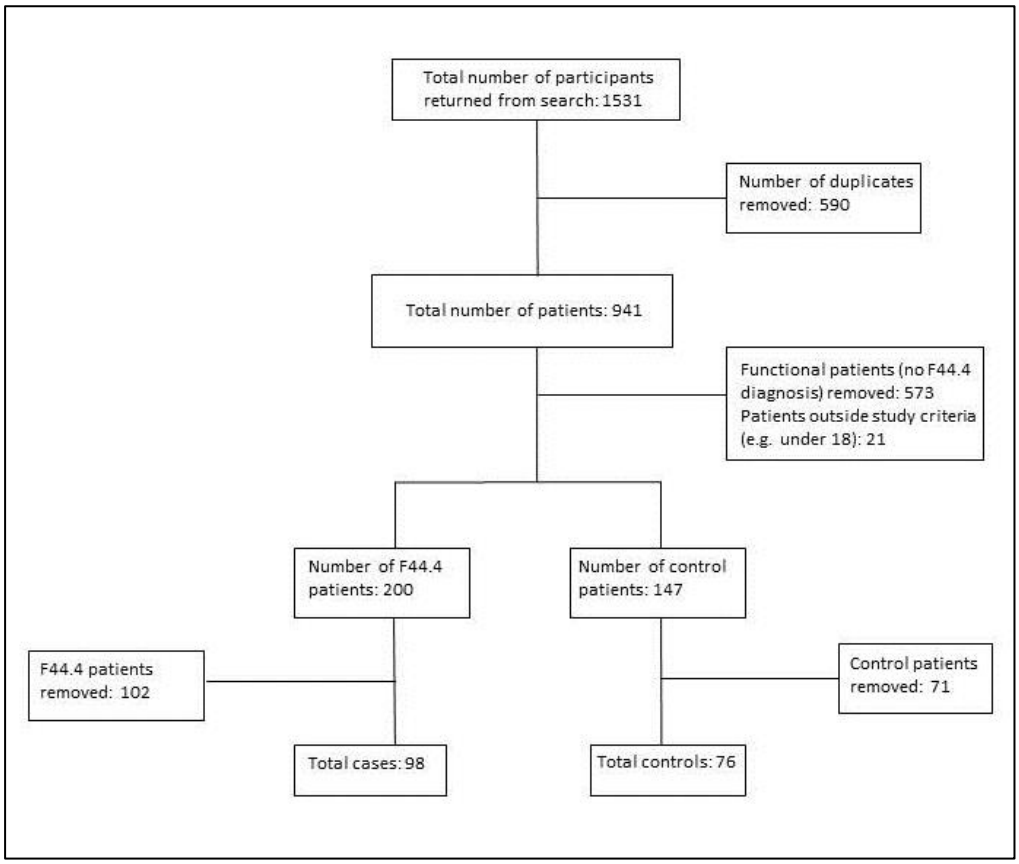

Figure 34 Flowchart showing total number of patients considered for study inclusion throughout study

One hundred and two FMD patients and 71 control patients were excluded from our analysis because they did not receive CBT treatment. These patients should be considered as 'pre-treatment dropout'. In these cases, CBT was suggested but they patient did not end up receiving it. This left a total of 98 FMD patients and 76 control patients in our study. Table 46 outlines the stage of the care pathway at which patients when excluded from our study.

Table 46 Stage of treatment pathway at which patients were excluded from treatment

Stage of treatment pathway at which patients were excluded	F44.4 Group n (%)	Control Group n (%)	χ2	95% CI	*p* value
Referred for assessment, excluded	24 (23.3)	33 (46.5)	10.01	7.8 - 37.5	**0.002**
Assessed, excluded	21 (20.6)	7 (9.9)	3.5	-1.2 – 21.5	0.06
Referred for treatment, excluded	20 (19.6)	17 (23.9)	4.3	-8.7 – 18	0.5
Inpatient at Lishman Unit, excluded	37 (36.3)	14 (19.7)	5.5	2.1 – 30	**0.02**
Total	102 (100)	71 (100)			

36.3% of excluded FMD patients and 19.7% of excluded control patients were treated in the neuropsychiatry inpatient setting, the Lishman Unit (see Table 46). Of the remaining patients,

65 FMD and 57 control group patients were excluded at the point they were referred for assessment, at the stage they received an assessment, or after they received a referral for treatment. The reasons why they were excluded at these stages are outlined in Table 47.

These reasons why FMD and control group patients were excluded at pre-CBT treatment were compared. Apart from admission to the Lishman Unit, the most common reason potential FMD patients were excluded was because they did not attend an assessment or treatment appointment (29.2% of excluded participants). The most common reason for exclusion amongst the control group was because there was no information on treatment sessions available in their notes (38.6% of excluded participants) and this reason was significantly more common in the control compared to the FMD group (χ2: 12.8, 95% CI: 11.6 – 43, p = 0.0003). A significantly higher proportion of FMD patients refused treatment compared to control group participants (χ2: 8.6, 95% CI: 5.4 – 30.3, p = 0.03). All exclusion causes are outlined in Table 47.

Table 47 Breakdown of reasons for pre-CBT treatment dropout

	F44.4 Group n (%)	Control Group n (%)	χ2	95% CI	*p* value
Did not attend assessment or treatment appointment	19 (29.2)	19 (33.3)	4.1	-13.2 - 21	0.6
No information in notes	7 (10.8)	22 (38.6)	12.8	11.6 – 43	**0.0003**
Local PCT declined funding	7 (10.8)	5 (8.8)	0.14	-10.3 – 13.7	0.7
Received treatment elsewhere	6 (9.2)	3 (5.3)	0.7	-7 – 14.5	0.4
Patient decided clinic too far or wanted treatment locally	4 (6.2)	1 (1.8)	1.5	-4.4 – 13.4	0.2
Patient refused treatment	14 (21.5)	2 (3.5)	8.6	5.4 – 30.3	**0.003**
Harm to patient (e.g. hospitalisation, self-harm or suicide before treatment)	1 (1.5)	2 (3.5)	0.5	-5.4 – 10.7	0.5
Staff decided patient wouldn't respond to or engage with treatment	4 (6.2)	1 (1.8)	1.5	-4.5 – 13.4	0.2
Staff decided patient wasn't suitable for treatment	3 (4.6)	1 (1.8)	0.7	-5.7 – 11.3	0.4
Total	65 (100)	57 (100)			

PCT: Primary care trust

6.2.4 Measures

Data were taken from both unstructured and structured fields in CRIS. Unstructured fields include patients' notes, correspondence and events. Structured fields included outcomes like date of birth, clinical outcome scores and diagnoses.

Demographic and clinical variables were extracted for all participants including year of birth, gender, ethnicity, marital status, employment status, housing status, benefits, carer status,

patients' first ICD-10 diagnosis received in SLaM and any subsequent diagnosis that was categorically different from the first.

Health variables included the most recent available information on smoking status, the most recent available BMI score, and information on any psychiatric inpatient admissions and discharges.

Life event information was collected which included any experience of childhood sexual or physical abuse (classified as experienced under the age of 18) or any experience of sexual or physical abuse over the age of 18. Additionally, any positive family history of a mental health problem was recorded including the relationship to the patient and what the condition was.

Acceptance of psychological accounts of symptoms was assessed from unstructured text before the patient started treatment and at the end of treatment. This was assessed as a five-point categorical variable as, 'yes', 'no', 'patient unsure', 'information not known' or 'not applicable'.

CBT attendance was recorded as the number of CBT sessions offered and the number of actual sessions attended. If there was a discrepancy between the two, the reason was recorded. The date in which patients attended their assessment session was collected along with the date of their first and last treatment session, and their last follow-up session.

Information on dropout and its reasons was taken and, if available, we defined dropout as the early cessation of treatment.

The following sections describe in more detail the measures used regarding 'patient improvement' and clinical outcome scores.

6.2.4.1 Patient improvement

Clinical outcome measures were recorded when available. A scoring system was agreed upon by the study team which was comprised of a three point scale, 'patients' symptoms improved', 'symptoms remained the same', or 'symptoms got worse'.

Control patients' improvement was based on individual patients' primary goal set in therapy. Often this goal was not symptom-specific, but instead related to day-to-day functioning or mood.

Pre-CBT scores were those classified as occurring nearest to the patients' CBT assessment date and post-CBT scores were those taken nearest to the final CBT treatment session or follow-up

session. A cut-off of 180 days was used. If a score was measured 180 days before or after the date in question, it was excluded.

Clinical outcome scores included Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM), HoNOS, HoNOS-ABI and PHQ-9 scores. Below is an account of the psychometric properties of the CORE-OM measure. For further detail on the properties of HoNOS, HoNOS-ABI and PHQ-9 measures see Sections 5.2.3.2, 5.2.3.3, and 5.2.3.4 respectively.

6.2.4.2 CORE-OM

The CORE-OM is a self-report questionnaire measuring psychological distress and is used to assess the outcome of psychological therapies. The questionnaire covers four domains relating to specific problems such as depression, anxiety and trauma, functioning in everyday life and relationships, subjective well-being, and risks to self and others.

The measure contains 34 items and all items are scored on a five point scale (0 – 4) relating to the previous week. The measure takes between 5-10 minutes to complete. It was specifically designed for assessment and treatment evaluation and contains both high and low intensity items which relate to a patient's overall emotional wellbeing. An example of a low intensity item includes, "I have been able to do most things I needed to" while a high intensity item is, "I have felt panic or terror". A recommended cut-off between clinical and normal populations is a score of 10, a score derived from large samples of the UK population (Connell et al., 2007). A reliable change is considered to be five or more. Clinically significant change is indicated when a client's CORE score moves from within the clinical range to that of the non-clinical population (below ten after therapy). The score presented in our study is the mean item score multiplied by ten, giving the clinical score.

The CORE-OM has good criterion validity. Its correlation with the Beck Depression Inventory is $r = 0.85$. It has high internal consistency for secondary care ($\alpha = 0.95$) and primary care settings ($\alpha = 0.93$) (Barkham et al. 2005), and similarly high internal consistency scores for non-clinical samples ($\alpha = 0.94$) (Barkham et al., 2001). A one-week test-retest correlation in a student sample of 43 participants was reported with a Spearman's rho = 0.90 (Evans et al., 2002).

The measure has been used to assess emotional well-being in a wide range of conditions and settings such as the treatment of depression in primary care (Gilbody et al., 2007), the outcomes of patients receiving CBT in primary and secondary care (Stiles et al., 2006), online CBT (Richards et al., 2013), and for patients with functional symptoms referred from neurology outpatients to psychotherapy (Reuber et al., 2007).

6.2.5 Statistical analysis

Data were analysed using SPSS (IBM SPSS Statistics for Windows, Version 22.0, Armonk, NY: IBM Corp). Graphs were made using GraphPad Prism (version 7.00 for Windows, La Jolla California, USA).

Descriptive statistics using means, standard deviations, count, and frequency data were used to assess differences between FMD and control groups. Differences between groups were calculated using Chi-square analyses for frequency data, *t*-test comparisons for normally distributed mean scores, and Mann-Whitney U calculations for non-normal comparisons. An exact McNemar's test was used to determine the change in proportion of patients accepting the role of a psychological explanation for symptoms. A repeated measures ANOVA was conducted to assess the change in CORE-OM, scores and their associations with socio-demographic variables. A binary logistic regression analysis was used to assess the socio-demographic variables associated with treatment dropout in FMD patients.

6.3 Results

6.3.1 Participants

In total, there were 98 FMD patients and 76 control group patients.

There were significantly more females in the FMD group (71, 72.4%) compared to females in the control group (34, 44.7%) (χ^2: 13.6, 95% CI: 12.2 – 41.9, p = 0.001).

No significant differences in ethnicity between the FMD and control group. Britishness was the most common ethnicity in both the FMD (67.3%) and control (71.1%) groups.

42.9% of the FMD group was single and a slightly higher proportion of control group patients were single (57.9%). 41.8% of the FMD group was married compared to 32.9% of the control group however there were no statistical differences in any type of marital status between groups.

The most frequent form of housing type for FMD patients was privately owned accommodation (42.3%). Just under half of the control group lived in privately owned accommodation at 47.6%. Rates of residency in council accommodation, privately rented, or supported and temporary accommodation were similar across groups. There was a slight difference between groups in the rates of participants living with family members, with 25.6% of the FMD and 19% of control group patients. There were no statistical differences in any type

of accommodation between groups. See Table 48 for a full breakdown of frequencies of gender, ethnicity, marital status, and housing for FMD and control groups.

Table 48 Gender, ethnicity and marital status of F44.4 and control group patients

	F44.4 Group n (%)	Control group n (%)	χ^2	95% CI	*p* value
Gender					
Female	71 (72.4)	34 (44.7)	13.6	12.2 – 41.9	**0.001**
Male	27 (27.6)	42 (55.3)			
Ethnicity					
British	66 (67.3)	54 (71.1)	0.3	-10.9 – 18	0.60
Any other ethnic group	10 (10.2)	4 (5.3)	1.4	- 4.4 – 13.6	0.24
Any other black background	9 (9.2)	2 (2.6)	3.1	-1.6 – 14.5	0.08
Any other white background	5 (5.1)	7 (9.2)	1.1	-4.3 – 13.6	0.30
Any other Asian background	4 (4.1)	1 (1.3)	1.2	-3.7 – 9	0.27
African	2 (2)	3 (3.9)	0.6	-4.1 – 9.3	0.46
Caribbean	1 (1)	2 (2.6)	0.65	-3.5 – 8.2	0.42
Indian	0 (0)	2 (2.6)	2.6	-1.7 – 9.1	0.11
Not known	1 (1.3)	1 (1.3)	0	-4.9 – 5.9	1
Marital status					
Single	42 (42.9)	44 (57.9)	3.8	- 0.8 – 30	0.051
Married or civil partner	41 (41.8)	25 (32.9)	1.4	-6.4 – 23.6	0.23
Divorced/Separated	9 (9.2)	4 (5.3)	0.9	-5.2 – 12.4	0.33
Cohabiting	4 (4.1)	2 (2.6)	0.29	-5.7 – 8	0.60
Widowed	2 (2)	1 (1.3)	0.13	-5.4 – 6	0.72
Housing Type					
Council tenant	10 (12.8)	7 (11.1)	0.09	-10.6 – 13.2	0.76
Living with family	20 (25.6)	12 (19)	0.86	-8.4 – 20.8	0.35
Privately owned	33 (42.3)	30 (47.6)	0.39	-12 - 22.4	0.53
Privately rented	14 (17.9)	13 (20.6)	0.16	-11.1 – 17	0.69
Other*	1 (1.3)	1 (1.6)	0.02	-5.6 – 7.4	0.88
Not known	20 (20.4)	13 (17.1)			

* Supported and temporary accommodation

At the point of analysis, the average age of FMD patients was 44.5 years (SD: 12). The average age of participants in the control group was 45.4 years (SD: 13) and there were no significant differences in age between groups.

The average age at which psychological symptoms began in the FMD group was 30 years (SD: 14), compared to 27.8 years (SD: 15) in the control group. This difference was not statistically significant.

On average, there was a ten-year gap between symptom onset amongst FMD patients and their CBT assessment at the neuropsychiatry clinic. The mean age at which they received this assessment was 40.3 years of age (SD: 13), the same in the control group at 40.7 years of age (SD: 13).

Participants were stratified by gender to assess whether there were any age differences between FMD and control groups. No differences in age emerged between groups for either males or females. See Table 49 for a full breakdown of patients' age at analysis, symptom onset and CBT assessment.

Table 49 Age at analysis, symptom onset and assessment for F44.4 and control groups

	F44.4 Group	Control Group	test	95% CI	*p* value
Mean age (SD)					
Age at analysis[1]	44.5 (12)	45.4 (13)	1.3	-1.4 – 7.4	0.19
Age at psychological symptom onset[2]	30 (14)	27.8 (15)	3105.5		0.27
Age at CBT assessment[2]	40.3 (13)	40.7 (13)	3669		0.87
Mean age v gender					
Female age of symptom onset [2]	28.9 (13)	27.4 (14)	1043		0.49
Male age of symptom onset[2]	33 (15)	28 (15)	404.5		0.15
Female age at CBT assessment[2]	39.9 (13)	41.2 (12)	1134.5		0.62
Male age at CBT assessment[2]	41.5 (13)	40.3 (13)	539		0.73

[1]Independent samples *t*-test comparing mean age
[2] Mann-Whitney U test

The most recent data on employment was collected for both groups. A smaller proportion of FMD patients was employed compared to the control group (34% v. 48.7%) but the difference was not statistically significant.

52.6% of the FMD group was unemployed compared to 35.5% of the control group, a statistically significant difference (χ2: 5, 95% CI: 1.4 – 31.9, p = 0.03). There were no other significant differences in employment rates between groups. 5.2% of the FMD group were medically retired.

Unemployment was stratified by gender. There was a significant difference in the gender ratios of patients who were unemployed. A higher proportion of females was unemployed compared to females in the control group (74.5% versus 40.7%, χ2: 8.5, 95% CI: 8.9 – 55.3, p = 0.004).

Information was collected on whether participants were employed pre-morbidly. The rates were high in both groups, with 94.6% of the FMD and 91.7% of the control group employed prior to the onset of their symptoms. There was no statistical difference.

Over a third of the FMD group received benefits (39.6%) but this did not differ significantly from the control group (35.7%). The most common type of benefit received by participants was Personal Independence Allowance (previously known as DLA). There were no statistical differences in the type of benefits received by participants between groups. Table 50 gives a full breakdown of employment rates and benefits for the FMD and control group participants.

Table 50 Employment and benefit status of functional motor and control group patients.

	F44.4 Group n (%)	Control Group n (%)	χ2	95% CI	*p* value
Employment					
Employed	33 (34)	37 (48.7)	3.8	-0.8 – 29.7	0.051
Unemployed	51 (52.6)	27 (35.5)	5	1.4 – 31.9	**0.03**
Retired	4 (4.1)	3 (3.9)	0.004	-7.5 – 7.0	0.94
Sick leave	3 (3.1)	0 (0)	2.4	-2.2 – 8.8	0.12
Student	1 (1)	2 (2.6)	0.65	-3.5 – 8.2	0.42
Voluntary work	0 (0)	3 (3.9)	3.8	-1.0 – 11.0	0.0504
Medically retired	5 (5.2)	4 (5.3)	0.001	-7.4 – 8.5	0.97
Not known	1 (1)	0 (0)			
Unemployed					
Female n (%)	38 (74.5)	11 (40.7)	8.5	8.9 – 55.3	**0.004**
Male n (%)	13 (25.5)	16 (59.3)			
Employed pre-morbidly?					
Yes	88 (94.6)	66 (91.7)	1.06	-4.4 – 13.5	0.30
No	5 (5.4)	4 (5.6)	0.003	-7.7 – 9.20	0.96
Not applicable	0 (0)	2 (2.8)			
Not known	5 (5.1)	4 (5.3)			
Benefits*					
Receives benefits	36 (39.6)	25 (35.7)	0.25	-12.1 – 19.4	0.61
Does not receive benefits	55 (60.4)	45 (64.3)			
Not known	7 (7.1)	6 (7.9)			
Disability Living Allowance/Personal Independence Allowance	14 (37.8)	11 (57.9)	2.1	-9.9 – 46.8	0.16
Employment Support Allowance (formerly Incapacity Benefit)	7 (18.9)	1 (5.3)	1.9	-9.9 – 30.6	0.17
Housing Benefit	4 (10.8)	0 (0)	2.2	-8.5 – 25.4	0.14
Income Support Allowance	4 (10.8)	4 (21.1)	1.1	-10.7 – 36	0.31
Illness Benefit	3 (8.1)	0 (0)	1.6	-10.7 – 21.9	0.21
Child Benefit/Child Tax Credit	3 (8.1)	2 (10.5)	0.09	-14.2 – 25.9	0.77
Carer's Allowance	1 (2.7)	0 (0)	0.5	-15.1 – 14.2	0.47
Job Seeker's Allowance	0 (0)	1 (5.3)	2.0	-5.5 – 26.1	0.16
Freedom Pass	1 (2.7)	0 (0)	0.5	-15.1 – 14.2	0.5
Total	37 (100)	19 (100)			

*19 patients received more than one type of benefit

In Chapter Five, social and healthcare work emerged as a common occupation amongst FMD patients. This was assessed again in this study. The current or most recently held position was recorded.

While patients in the FMD group were more likely to work in social and health care settings (21.3% versus 14.9%), the numbers were low and the difference was not statistically different. When broken down by gender, a difference emerged. All FMD patients who worked in social or health care settings were women compared to 63.6% in the control group (χ^2: 8.1, 95% CI: 5.9 – 69.2, p = 0.005).

FMD patients were significantly more likely to be a carer than patients in the control group (11.8% v 2.7% χ2: 4.7, 95% CI: 0.2 -17.8, *p* = 0.03). There were no gender differences in rates of carers between groups.

More FMD than control group patients had a carer (27.6% v 14.3%, χ2: 4.1, 95% CI: - 0.5 – 26.1, *p* = 0.005). When this was assessed by gender, there were no differences between groups.

Table 51 outlines the rates of patients working in social and healthcare settings and carer status.

Table 51 History of employment in social care and health settings and carer status for functional motor and control group patients

	F44.4 Group n (%)	Control Group n (%)	χ2	95% CI	*p* value
Social or health care worker					
Yes	20 (21.3)	11 (14.9)	1.1	-6.4 – 18.5	0.29
No	74 (78.7)	63 (85.1)			
Not known	4 (4.1)	2 (2.6)			
Female social/health worker	20 (100)	7 (63.6)	8.1	5.9 – 69.2	**0.005**
Male social/health worker	0 (0)	4 (36.4)			
Carer					
Yes	11 (11.8)	2 (2.7)	4.7	0.2 – 17.8	**0.03**
No	82 (88.2)	72 (97.3)			
Not known	5 (5.1)	2 (2.6)			
Female carer	7 (63.6)	1 (50)	0.1	-45.2 – 68.6	0.72
Male carer	4 (36.4)	1 (50)			
Has a carer?					
Yes	24 (27.6)	10 (14.3)	4.1	- 0.5 – 26.1	**0.005**
No	63 (72.4)	60 (85.7)			
Not known	11 (11.2)	6 (7.9)			
Females with a carer	17 (70.8)	5 (50)	1.3	-17.4 – 56.2	0.3
Males with a carer	7 (29.2)	5 (50)			

6.3.2 Diagnoses

6.3.2.1 ICD-10 diagnoses

The first diagnosis received by each participant from SLaM was recorded. In the FMD group 48 (50.5%) participants received a neurotic, stress-related or somatoform disorder diagnosis (F40 – F48) when first diagnosed in SLaM, and 20 (21.1%) were given an unspecified mental disorder (F99) diagnosis.

For control group participants, the most common first diagnosis from SLaM was within the category of diseases of the nervous system (G00-G99) (28.4% of participants), followed by an F99 diagnosis (17.6%), and mood disorders (F30-F39) (13.5% of participants).

A second diagnosis was recorded for participants if the first diagnosis changed. Forty-two (42.9%) FMD patients received a second diagnosis. Twenty-four (31.6%) control group participants received a second diagnosis. Again, the most frequent type of diagnosis from SLaM was a neurotic, stress-related and somatoform disorder (66.7%) followed by an F99 diagnosis (14.3%). Control group patients' most common second SLaM diagnosis was a neurotic, stress-related and somatoform disorder (20.8%), followed by behavioural and emotional disorders with onset in childhood and adolescence (16.7%).

Fourteen (14.3%) FMD participants received a third SLaM diagnosis. The most common type of diagnosis was within the neurotic, stress-related and somatoform disorders category (78.6%). Four (5.3%) control group received a third ICD-10 diagnosis and half of these were mood disorders. Table 52 outlines the first, second and third diagnoses received by participants.

The control group consisted of participants who had an organic disorder and comorbid psychiatric complaints. Control group participants were chosen if they had an organic disease for which they were receiving CBT treatment. The data displayed in Table 53 outlines control patients' ICD-10 diagnoses in more detail. These data are from the structured fields within CRIS. In some cases, an official ICD-10 diagnosis will not be recorded within these fields. If this was the case, information on diagnosis and symptoms was taken from unstructured text, such as notes or correspondence.

The most frequent type of control group diagnosis was disease of the nervous system. Of these, unspecified epilepsy was the most common disorder (47.6% of nervous diseases), followed by epilepsy and recurrent seizures (28.6% of nervous diseases). The next most common type of physical disorder was Tourette's syndrome (66.7% of behavioural and emotional disorders with onset in childhood and adolescence).

Table 52 First, second and third psychiatric diagnoses received by F44.4 and control groups in SLaM Trust

	First SLaM Diagnosis		Second SLaM Diagnosis		Third SLaM Diagnosis	
	F44.4 Group (%)	Control Group n (%)	F44.4 Group n (%)	Control Group n (%)	F44.4 Group n (%)	Control Group n (%)
ICD-10 psychiatric diagnosis received from SLaM						
(F00-F09) Organic, including symptomatic, mental disorders	2 (2.1)	4 (5.4)	0 (0)	2 (8.3)	0 (0)	0 (0)
(F10-F19) Mental and behavioural disorders due to psychoactive substances	0 (0)	1 (1.4)	1 (2.4)	1 (4.2)	0 (0)	0 (0)
(F20 – F29) Schizophrenia, schizotypal and delusional disorders	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
(F30 – F39) Mood (affective) disorders	1 (1.1)	10 (13.5)	6 (14.3)	6 (25)	0 (0)	2 (50)
(F40 – F48) Neurotic, stress-related and somatoform disorders	48 (50.5)	8 (10.8)	28 (66.7)	5 (20.8)	11 (78.6)	1 (25)
(F50 – F59) Behavioural syndromes associated with physiological disturbances and physical factors	0 (0)	2 (2.7)	0 (0)	0 (0)	1 (7.1)	0 (0)
(F60 – F69) Disorders of adult personality and behaviour	0 (0)	0 (0)	1 (2.4)	1 (4.2)	1 (7.1)	0 (0)
(F70 – F79) Intellectual disabilities	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
(F80 – F89) Disorders of psychological development	1 (1.1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
(F90 – F98) Behavioural and emotional disorders with onset in childhood and adolescence	1 (1.1)	9 (12.2)	0 (0)	4 (16.7)	0 (0)	0 (0)
(F99) Unspecified mental disorder	20 (21.1)	13 (17.6)	6 (14.3)	1 (4.2)	1 (7.1)	1 (25)
Other diagnoses						
(FXX)	4 (4.2)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
(Z00 – Z99) Factors influencing health status and contact in health services	15 (15.8)	5 (6.8)	0 (0)	1 (4.2)	0 (0)	0 (0)
(F00-F99) Mental, behavioural and neurodevelopmental disorders	0 (0)	1 (1.4)	0 (0)	0 (0)	0 (0)	0 (0)
(G00-G99) Diseases of the nervous system	1 (1.1)	21 (28.4)	0 (0)	3 (12.5)	0 (0)	0 (0)
(M00-M99) Diseases of the musculoskeletal system and connective tissue	2 (2.1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Not known	3 (3.1)	2 (2.6)	0 (0)	0 (0)	0 (0)	0 (0)
Total	98 (100)	76 (100)	42 (100)	24 (100)	14 (100)	4 (100)

Table 53 Breakdown of first, second and third control group diagnoses

	First SLaM diagnosis	Second SLaM diagnosis	Third SLaM diagnosis
ICD-10 psychiatric diagnosis received from SLaM			
(F00-F09) Organic, including symptomatic, mental disorders	4 (5.4)	2 (8.3)	0 (0)
(F10-F19) Mental and behavioural disorders due to psychoactive substances	1 (1.4)	1 (4.2)	0 (0)
(F20 – F29) Schizophrenia, schizotypal and delusional disorders	0 (0)	0 (0)	0 (0)
(F30 – F39) Mood (affective) disorders	10 (13.5)	6 (25)	2 (50)
(F40 – F48) Neurotic, stress-related and somatoform disorders	8 (10.8)	5 (20.8)	1 (25)
(F50 – F59) Behavioural syndromes associated with physiological disturbances and physical factors	2 (2.7)	0 (0)	0 (0)
(F60 – F69) Disorders of adult personality and behaviour	0 (0)	1 (4.2)	0 (0)
(F70 – F79) Intellectual disabilities	0 (0)	0 (0)	0 (0)
(F80 – F89) Disorders of psychological development	0 (0)	0 (0)	0 (0)
(F90 – F98) Behavioural and emotional disorders with onset in in childhood and adolescence	9 (12.2)	4 (16.7)	0 (0)
F95 Tic disorder	3 (33.3)	0 (0)	0 (0)
F95.2 Tourette's disorder	6 (66.7)	3 (75)	0 (0)
F95.9 Tic disorder, unspecified	0 (0)	1 (25)	0 (0)
(F99) Unspecified mental disorder	13 (17.6)	1 (4.2)	1 (25)
(FXX)	0 (0)	0 (0)	0 (0)
(Z00 – Z99) Factors influencing health status and contact in health services	5 (6.8)	1 (4.2)	0 (0)
(F00-F99) Mental, behavioural and neurodevelopmental disorders	1 (1.4)	0 (0)	0 (0)
(G00-G99) Diseases of the nervous system	21 (28.4)	3 (12.5)	0 (0)
(G20.X) Parkinson's disease	2 (9.5)	0 (0)	0 (0)
(G40) Epilepsy and recurrent seizures	6 (28.6)	0 (0)	0 (0)
(G40.0) Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset	1 (4.8)	0 (0)	0 (0)
(G40.2) Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizure	1 (4.8)	0 (0)	0 (0)
(G40.4) Other generalized epilepsy and epileptic syndromes	1 (4.8)	0 (0)	0 (0)
G40.9 Epilepsy, unspecified	10 (47.6)	1 (33.3)	0 (0)
(M00-M99) Diseases of the musculoskeletal system and connective tissue	0 (0)	0 (0)	0 (0)
Not known	2 (2.6)	0 (0)	0 (0)
Total	76 (100)	24 (100)	4 (100)

6.3.2.2 Functional motor symptomatology

The kind of symptoms experienced by FMD patients was classified according to their type and the area of the body in which it occurred. Symptom types were divided into five broad

categories of tremor, weakness, numbness, paralysis, and pain. Some symptoms did not naturally fit this classification, like slurred speech, visual disturbance, and gait disturbance.

It was common for participants to have more than one symptom. All participants had at least one motor symptom for which they were receiving treatment. Eighty-two participants (83.7%) had two symptoms, 40 participants (40.8%) had three symptoms, and 12 (12.2%) participants had four symptoms.

The most common symptom type was weakness affecting 47 patients (26.9%), most frequently occurring in the leg or the entire body. After weakness, pain was most frequently reported by participants, affecting 46 patients (26.3%), followed by tremor. The tremor category incorporated symptoms such as shaking, tremor, jerking, and dystonia. Pain in the back or chest was also common, affecting 17 participants. Twenty-two participants had gait disturbance. Of all body regions, the area most frequently affected was the leg, occurring in 27 cases (15.4%). Table 54 displays a heat map outlining the most common combinations of symptoms and the region of the body in which they occurred.

Table 54 Heat map displaying the frequency of functional motor symptom type and the body region affected

	Tremor	Weakness	Numbness	Paralysis	Pain	Total n (%)
Hand	8	0	0	1	1	10 (5.7)
Leg	1	14	7	2	3	27 (15.4)
Not known	3	3	1	0	4	11 (6.3)
Unilateral body	4	13	5	1	2	25 (14.3)
Bilateral body	12	1	1	6	5	25 (14.3)
All limbs	4	7	5	1	1	18 (10.3)
Arm	6	5	2	0	7	20 (11.4)
Face/Head	2	2	4	0	1	9 (5.1)
Back/chest	2	1	0	0	17	20 (11.4)
Mouth	0	1	1	0	1	3 (1.7)
Feet/ankle	0	0	2	0	2	4 (2.3)
Eyes	1	0	0	0	2	3 (1.7)
Total	43 (24.6)	47 (26.9)	28 (16)	11 (6.3)	46 (26.3)	175 (100)

Specific symptoms were not included in this table including: 22 patients with gait disturbance, 16 with slurred speech, stammering or swallowing difficulties, 9 with blindness or visual disturbance, 6 with incontinence and 2 with hearing loss

In a separate analysis, the classification used by McCormack et al. (2014) was applied. This grouped symptoms as ‘abnormal’, ‘defined by loss’, or both. Thirty-nine FMD patients (39.8%) had abnormal symptoms such as gait disturbance, visual disturbance or tremor. Twenty-three FMD patients (23.5%) presented with symptoms defined as ‘loss’. This includes weakness,

paralysis and numbness. The remaining 36 (36.7%) had symptoms characterised by both loss and abnormality.

6.3.3 Health

The latest available information on patients' smoking status was assessed. Data were available for 75.5% of FMD and 73.7% of control patients.

40.5% of the FMD group and 35.7% of the control group smoked. There was no statistical difference in rates between groups. Data suggests that the rate of smoking in the English adult public is 19% (Health and Social Care Information Centre, 2015). The rate of smoking in the FMD and control groups is therefore considerably higher than the English public.

When data were stratified by gender, age and employment status, no statistical differences between groups in rates of smoking emerged. Table 55 gives a full breakdown of the rates of smoking in both groups.

Table 55 Table showing differences in smoking frequency and BMI mean scores between F44.4 and control groups

	F44.4 Group n (%)	Control Group n (%)	OR	95% CIs	*p* value	Rate in English adults
Smoking						
Yes	30 (40.5)	20 (35.7)	1.23	0.60 – 2.5	0.58	19%*
No	44 (59.5)	36 (64.3)				81%*
Not known	24 (24.5)	20 (26.3)				
Female smokers[1]	20 (38.5)	5 (20)	2.5	0.8 – 7.7	0.11	17%*
Male smokers[2]	10 (45.5)	15 (48.4)	0.89	0.3 – 2.7	0.83	24%*
Mean age smokers[3] (SD)	45.6 (9.4)	43.9 (12)	0.58	-4.3 – 7.7	0.57	
Employed[4]	10 (38.5)	10 (38.5)	1	0.3 – 3.1	1	19%*
Unemployed[5]	20 (41.7)	10 (33.3)	1.4	0.6 – 3.7	0.46	35%*
BMI normal range (18.5 – 24.9)						
Mean (SD)[3]	27.4 (12)	17.9 (7)	-	-	-	25.6**
Not known	92 (93.9)	72 (94.7)				
Female mean (SD)	28.3 (13.2)	-	-	-	-	26.9**
Male mean (SD)[6]	-	-	-	-	-	27.4**
Physical health condition						
Yes	76 (79.2)	76 (100)	0.02	0.001 – 0.04	**0.01**	
No	20 (20.8)	0 (0)				
Not known	2 (2)	0 (0)				

[1] Female smokers versus female non-smokers
[2] Male smokers versus male non-smokers
[3] Independent samples *t*-test (unequal variance assumed); BMI scores available for 6 FMD patients & 4 or control patients so no statistical comparisons made
[4] Employed smokers versus employed non-smokers
[5] Unemployed smokers versus unemployed non-smokers; excludes 'retired', 'medically retired', 'sick leave, 'student' & 'voluntary work' groups
[6] One control group score available, no analysis conducted
* Health and Social Care Information Centre (2015)
** Health Survey for England data from 2011 (Sperrin et al., 2016)

BMI data were gathered when available, but was only available for six FMD participants and four control group patients. Like smoking, the most recent available data in all cases was collected for each participant. FMD patients had a mean BMI score of 27.4 (SD: 12), slightly higher than the average English BMI score of 25.6. A BMI score above 24.9 is considered overweight. Control group patients had a mean BMI of 17.9 (SD: 7). Due to the low sample, statistical comparisons were not made.

Comorbid physical health conditions were assessed in all patients. In order to qualify for inclusion in the control group, all participants had to have an organic condition. The rate of physical health conditions in the control group is therefore 100%. The rate in the FMD group is 79.2%, a significantly lower (OR: 0.02, 95% CI: 0.001 – 0.04, $p < 0.05$).

6.3.4 Psychiatric inpatient stays

Whether or not patients received an inpatient admission in SLaM was recorded from information provided in the structured fields in CRIS. Rates of hospital admissions were low in both groups. 9.2% of FMD patients had received an inpatient admission, higher than the control group admission rate of 3.9%. There was no statistical difference between the groups. Of all patients receiving an admission, no patient was admitted more than once.

When stratified by gender, no differences in admission emerged between groups.

Of FMD patients admitted, the mean number of days they spent in hospital was 88.2 days (SD: 60) (range: 1 – 155 days) which was slightly lower in the control group at 75 days (SD: 69.3) (range: 26 – 124 days). There was no statistical difference between the groups.

See Table 56 for a breakdown of the frequency of psychiatric admission for FMD and control group patients as well as the mean number of days in which they were in hospital.

Table 56 Inpatient rates and days for F44.4 and control groups

	F44.4 Group n (%)	Control Group n (%)	OR	95% CI	*p* value
Inpatient stay?					
Yes	9 (9.2)	3 (3.9)	2.46	0.64 – 9.4	0.19
No	89 (90.8)	73 (96.1)			
Inpatient stay x gender					
Female[1]	7 (9.9)	1 (2.9)	3.6	0.43 – 30.6	0.24
Male[2]	2 (7.4)	2 (4.8)	1.6	0.21 – 12.1	0.65
No. of inpatient days					
Mean (SD)*	88.2 (60)	75 (69.3)	0.28	-94.2 - 121	0.79
Females mean (SD)	74.4 (61)	124	-		
Males mean (SD)	136.5 (6.4)	26	-		

[1] Females with an inpatient stay versus females with no inpatient stay
[2] Males with an inpatient stay versus males with no inpatient stay
* *t*-test

6.3.5 Life events

Any record in patients' notes of childhood physical or sexual abuse was recorded. CSA experience was not known in 18.4% of FMD patients and 19.7% of control group cases.

There was a significant difference in the experience of CSA. 23.8% of FMD patients experienced CSA, higher than the rate reported in the control group, at 8.2% (OR: 3.5, 95% CI: 1.2 – 10, $p = 0.02$). No differences emerged following the stratification of results by gender or family mental health history.

No information on CPA was available in 17.3% of FMD patients' notes and 18.4% of control group patients' notes. Similar rates of CPA were reported in both groups (28.4% of FMD and 21% of control group patients). There was no statistically significant difference between groups. No differences emerged after stratification by gender or family mental health history.

Whether or not a participant had experienced physical or sexual abuse after the age of 18 was recorded. In both groups, the rate of unknown exposure was 18.4%. FMD patients experienced more physical or sexual abuse in adulthood than in the control group (23.8% versus 16.1%) but there was no statistically significant difference and no differences emerged when rates were stratified according to gender or family mental health history.

Any evidence of family mental health problems was recorded and rates were compared between groups. The information was unknown in 18.4% of cases in both the FMD and control groups. Over half of FMD patients had a family member with a mental health disorder (65.4%), almost identical to the rate in the control group (66.7%). Females in both groups had higher rates of family members with a mental health problem compared to their male counterparts but there were no statistical differences between groups.

See Table 57 for a breakdown of the rates of childhood and adulthood exposure to sexual and physical abuse and the rate of family members with a mental health problem.

Table 57 Child and adult physical and sexual abuse rates for F44.4 and control groups

	F44.4 Group n (%)	Control Group n (%)	OR	95% CI	*p* value
History of child sexual abuse	19 (23.8)	5 (8.2)	3.5	1.2 – 10	**0.02**
Female[1]	18 (30)	3 (12.5)	3	0.8 – 11.3	0.11
Male[2]	1 (5)	2 (5.4)	0.9	0.08 – 10.8	0.94
Family mental health history[3]	11 (73.3)	2 (66.6)	1.4	0.1 – 20	0.81
Not known	18 (18.4)	15 (19.7)			
History of child physical abuse	23 (28.4)	13 (21)	1.5	0.7 – 3.3	0.3
Female[1]	19 (31.1)	7 (29.2)	0.8	0.3 – 2.3	0.6
Male[2]	4 (20)	6 (15.8)	1.3	0.3 – 5.4	0.7
Family mental health history[3]	14 (87.5)	6 (75)	2.3	0.3 – 20.7	0.45
Not known	17 (17.3)	14 (18.4)			
History of adult physical or sexual abuse	19 (23.8)	10 (16.1)	1.6	0.7 – 3.8	0.3
Female[1]	19 (31.6)	8 (30.8)	1.04	0.4 – 2.8	0.9
Male[2]	0 (0)	2 (5.5)	0.3	0.02 – 7.3	0.5
Family mental health history[3]	9 (75)	5 (71.4)	1.2	0.15 – 9.8	0.86
Not known	18 (18.4)	14 (18.4)			
History of family mental health problems	51 (65.4)	40 (66.7)	0.94	0.5 – 1.9	0.87
Female	37 (68.5)	19 (70.4)	0.92	0.34 – 2.5	0.87
Male	14 (58.3)	21 (63.6)	0.8	0.27 – 2.4	0.68
Not known	18 (18.4)	14 (18.4)			

[1] Females abused in F44.4 group versus females abused in control group
[2] Males in abused in F44.4 group versus males abused in control group
[3] Family mental health history in F44.4 group versus family mental health history in control group

6.3.6 Psychological comorbidity and acceptance of psychological explanations

Any mention of lifetime prevalence of anxiety, depression or fatigue within unstructured text was assessed. This does not reflect a formal diagnosis, simply a record of the patient experiencing these psychological factors at some stage in their life. Depression was a broad category including low mood, depression, suicidal thoughts or ideation. Anxiety was categorised as anxiety or stress that interfered with participants' everyday life. Fatigue was any experience of tiredness that was mentioned as something that interfered or interrupted the participant's normal everyday functioning, and that was considered by the clinician to be outside the bounds of normal, everyday fatigue.

80.2% of the FMD group had a mention of anxiety within their medical records, significantly lower than the anxiety rate found in the control group of 91.8% (χ^2: 4.4, 95% CI: 0.07 – 22.3, $p = 0.04$).

Depression had a similar incidence in both groups with 85.7% of FMD patients and 88.2% of control group patients.

Fatigue was more commonly reported in FMD patients' notes affecting 72.2% of patients compared to just over half of the control group at 55.4% (χ2: 4.3, 95% CI: 0.12 – 32.8, p = 0.04).

See Table 58 for a breakdown of rates across groups.

Table 58 Life-time prevalence of anxiety, depression and fatigue

	F44.4 Group n (%)	Control Group n (%)	χ^2	95% CI	p value
Anxiety	77 (80.2)	67 (91.8)	4.4	0.07 – 22.3	**0.04**
Not known	2 (2)	3 (3.9)			
Depression*	84 (85.7)	67 (88.2)	0.23	-8.8 – 13.1	0.63
Not known	-	-			
Fatigue	57 (72.2)	36 (55.4)	4.3	0.12 – 32.8	**0.04**
Not known	19 (19.4)	11 (14.5)			

Includes low mood, depression, suicidal thoughts, & suicidal ideation

The researcher assessed whether FMD patients accepted a psychological account or explanation of symptoms before they started CBT treatment and whether this had changed after treatment. As this was not a relevant component of control patients' treatment, this was not assessed.

Just under half of the FMD patients (49%) accepted a psychological explanation for their symptoms at the start of CBT treatment, a third (27.6%) did not accept a psychological account, 13.3% were not sure what the cause of their symptoms were, and in ten cases (10.2%) no information was available or a psychological account was not applicable to the patient.

After therapy, 71.6% accepted a psychological account of their symptoms and a lower proportion did not accept a psychological explanation (17.9%). Fewer participants were now unsure at 5.3%.

Table 59 outlines the rate of patients' acceptance of psychological explanations for symptoms before and after CBT therapy.

Table 59 Proportion of F44.4 patients who accept the role of psychological factors in their symptom presentation before and after therapy

	Yes n (%)	No n (%)	Patient unsure n (%)	Not known n (%)	NA n (%)
Accepted psychological factors before therapy?	48 (49)	27 (27.6)	13 (13.3)	9 (9.2)	1 (1)
Accepted psychological factors after therapy?	68 (71.6)	17 (17.9)	5 (5.3)	5 (5.3)	0 (0)

Acceptance of psychological symptom explanations was assessed in further detail to assess the proportion of patients who changed their acceptance of psychological factors before and after therapy.

Forty-six patients accepted a psychological explanation both before and after treatment. Nine patients didn't accept the role of psychological factors before treatment but by the end of treatment had changed their minds. Fourteen patients didn't accept the role of psychology either before or after treatment and no patient accepted a psychological account before treatment but rejected its role after therapy.

An exact McNemar's test determined that there was a statistically significant increase in the proportion of people accepting a psychological explanation for symptoms as a result of CBT (p = 0.004).

Table 60 outlines the proportion of FMD patients who accepted the role of psychology before and after therapy and the numbers who changed their acceptance over time.

Table 60 Proportion of F44.4 patients who accepted the role of psychology in their symptoms before and after therapy

		Accepted a psychological explanation after therapy?	
		Yes	No
Patient accepted role of psychological factors before therapy?	Yes	46	0
	No	9	14

6.3.7 CBT dropout

Four clinicians worked in the CBT clinic at the time of data collection. Some had worked there longer and had treated more patients. The number and proportion of patients treated by each clinician is outlined in Table 61. Clinician four treated the highest number of participants (44.3%) overall and the highest proportion of FMD patients (44.9%). Clinician one and two were more recent employees and had seen fewer patients at the time of analysis.

Table 61 Distribution of clinicians treating F44.4 and control groups

	F44.4 Group n (%)	Control Group n (%)	Total n (%)
Clinician one	9 (9.2)	3 (3.9)	12 (6.9)
Clinician two	12 (12.2)	6 (7.9)	18 (10.3)
Clinician three	33 (33.7)	34 (44.7)	67 (38.5)
Clinician four	44 (44.9)	33 (43.4)	77 (44.3)

Participants were at different stages of treatment when data were collected. In total, nine FMD patients were receiving on-going treatment (9.2% of the sample) at the time data was collected. Eleven control group participants were in the middle of their treatment sessions (14.5% of the control group sample).

The same rate of participants attended all sessions in both groups with 55 FMD patients (56.1%) and 43 control group patients (56.6%) attending all sessions offered. Twenty-eight FMD patients (28.6%) did not complete all sessions offered, compared to 20 control group participants (26.3%). In total, therapists decided to stop sessions early in six FMD cases and with two control patients. There were no statistically significant differences between attendance rates or reasons for dropout between the two groups.

Table 62 gives an overview of the rates of attendance and dropout for FMD and control patients.

Table 62 Attendance rates of functional motor and control group participants

	F44.4 Group n (%)	Control Group n (%)	χ^2	95% CI	*p* value
Attended all sessions	55 (56.1)	43 (56.6)	0.004	-15 – 15.9	0.95
Dropped out of treatment early	28 (28.6)	20 (26.3)	0.11	-12 – 16.1	0.74
Therapist stopped sessions	6 (6.1)	2 (2.6)	1.2	-4.1 – 10.6	0.27
Sessions on-going at time of data collection	9 (9.2)	11 (14.5)	1.2	-5 – 16.4	0.28
Total	98 (100)	76 (100)			

FMD patients who attended all CBT sessions were compared to FMD patients who dropped out early or whose therapist stopped sessions early.

Data were stratified by gender, marital status, ethnicity, employment, history of childhood sexual abuse, acceptance of the role of psychological factors prior to CBT, wheelchair use, age, improvement category, and CORE-OM, PHQ-9, and HoNOS-ABI scores.

There were no differences between therapy completers and participants who dropped out early according to socio-demographics, apart from patients who had experienced CSA and

patients who were classified as improving as a result of CBT therapy. FMD patients who dropped out of therapy early were more frequently victims of CSA compared to therapy completers (36.7% versus 16.3%, χ^2: 3.9, 95% CI: -1.7 – 42, p = 0.05) and patients who attended all CBT sessions were more likely to see their symptoms improve than patients who dropped out early (58.5% versus 29.2%, χ^2: 5.6, 95% CI: 3.1 – 50.6, p = 0.02).

Table 63 outlines the rates of FMD patients completing therapy compared to FMD patients who did not complete all sessions according to socio-demographic variables.

Table 63 Socio-demographic differences between F44.4 patients who attended all CBT sessions offered versus those who dropped out early

		Attended all sessions n (%)	Dropped out or therapist stopped n (%)	χ^2	95% CI	*p* value
Total		55 (61.8)	34 (34.7)	13	11.7 – 41.2	**0.003**
Gender	Female	42 (76.4)	23 (67.6)	0.82	-11.3 – 29.7	0.37
	Male	13 (23.6)	11 (32.4)			
Marital status	Single, divorced, widowed or separated	22 (48.9)	14 (48.3)	0.003	-23.9 – 24.9	0.96
	Married, civil partner or cohabiting	23 (51.1)	15 (51.7)			
Ethnicity	British	36 (65.5)	24 (70.6)	0.25	-16.8 – 25.1	0.62
	Other ethnicity	19 (34.5)	10 (29.4)			
Work	Employed	17 (30.9)	13 (39.4)	0.66	13.1 – 30.4	0.42
	Unemployed/retired/sick leave	38 (69.1)	20 (60.6)			
Abuse	History of CSA	7 (16.3)	11 (36.7)	3.9	-1.7 – 42	**0.05**
	No history of CSA	36 (83.7)	19 (63.3)			
Psych	Accepted psych role before	28 (68.3)	13 (48.1)	2.7	-5.6 – 44	0.10
	Didn't accept psych role before	13 (31.7)	14 (51.9)			
Disability	Uses wheelchair or walking aid	22 (43.1)	20 (60.6)	2.4	-6.1 – 39	0.12
	Walks unaided	29 (56.9)	13 (39.4)			
Age	Mean age at assessment[1] (SD)	39.1 (13)	41.7 (13)			0.73
Outcomes	Patient improved	31 (58.5)	7 (29.2)	5.6	3.1 – 50.6	**0.02**
	Patient got worse/stayed the same	22 (41.5)	17 (70.8)			
	Mean pre-CBT CORE-OM (SD)[2]	15.3 (6)	17.4 (7.8)	22.5		0.49
	Mean post-CBT CORE-OM (SD)[2]	10.2 (7)	9.4 (2.7)	28		0.86
	Mean pre-CBT PHQ-9 (SD)[3]	14.8 (6.2)	5 (5.7)	2.5		0.08
	Mean post-CBT PHQ-9 (SD)[3]	11.2 (5.1)	5 (7)	3.5		0.11
	Mean pre-CBT HoNOS-ABI (SD)[4]	12.4 (6.5)	8.2 (4)	24.5		0.16
	Mean post-CBT HoNOS-ABI (SD)[4]	6.9 (5.5)	8.6 (4)	5.5		0.73

[1] Mann-Whitney U test
[2] Mann-Whitney U test, data from 20 attenders and 3 drop out patients
[3] Mann Whitney U test, data from 13 F44.4 attenders and 2 F44.4 drop out patients
[4] Mann-Whitney U test, data from 17 F44.4 attenders and five F44.4 drop out patients

A logistic regression was performed to ascertain the effects of gender, marital status, ethnicity, employment, CSA, symptom improvement, acceptance of psychological explanations before therapy, and wheelchair use on the likelihood that participants would drop out of CBT therapy. No significant associations were detected between any of these independent variables and

patient dropout. The logistic regression model was not statistically significant (χ^2 (8) = 7.5, p = 0.49) and the model explained 21.4% (Nagelkerke R^2) of the attendance to CBT.

Comparisons were made between FMD and control patients who completed all therapy sessions by socio-demographic variables. Of therapy completers, more female FMD patients completed therapy compared to female control group patients (76.4% versus 48.8%, χ2: 7.9, 95% CI: 7 – 46.3, p = 0.005). No other socio-demographic differences emerged between the FMD and control group therapy completers.

Participants who dropped out of therapy early where grouped with patients whose therapists had stopped sessions and the profile of FMD and control group patients was compared. Of patients who dropped out early, control patients were more frequently single than FMD patients (78.9% versus 48.3%, χ2: 4.4, 95% CI: -0.53 – 54.7, p = 0.04) while FMD patients who dropped out were more likely to have experienced CSA (χ2: 3.9, 95% CI: -3 – 51.1, p = 0.05).

Table 64 outlines the socio-demographic differences between FMD and control groups comparing patients who attended all sessions versus those who dropped out early.

Table 64 Socio-demographic differences between F44.4 and control patients grouped by their attendance at CBT

	F44.4 Group n (%)	Control Group n (%)	χ^2	95% CI	*p* value
Attended all CBT sessions offered	55 (56.1)	43 (56.6)	0.004	-15 - 15.9	0.95
Female	42 (76.4)	21 (48.8)	7.9	7 – 46.3	**0.005**
Male	13 (23.6)	22 (51.2)			
Single	22 (48.9)	21 (53.8)	0.20	-17.7 – 27	0.66
Married	23 (51.1)	18 (46.2)			
British	36 (65.5)	32 (74.4)	0.89	-10.9 – 27.4	0.35
Other ethnicity	19 (34.5)	11 (25.6)			
Employed	17 (30.9)	21 (48.8)	3.2	-2.9 – 37.5	0.07
Unemployed, retired, sick leave	38 (69.1)	22 (51.2)			
History of CSA	7 (16.3)	3 (8.8)	1.19	-7.8 – 21.5	0.28
No history of CSA	36 (83.7)	31 (91.2)			
Mean age at assessment (SD)[1]	39.1 (13)	40.4 (12)			0.61
Patient improved after CBT	31 (58.5)	30 (69.8)	1.3	-9.5 – 30.7	0.26
Patient worse/same after CBT	22 (41.5)	13 (30.2)			
Pre-CBT CORE-OM score (SD)[2]	15.3 (6)	16.4 (7)	-0.54	-5.3 – 3.1	0.59
Post-CBT CORE-OM score (SD)[2]	10.2 (7)	12.7 (7)	-1.1	-6.9 – 1.9	0.26
Pre-CBT PHQ-9 score (SD)[2]	14.8 (6.2)	12.8 (10)	0.51	-6.8 – 10.8	0.62
Post-CBT PHQ-9 score (SD)[2]	11.2 (5.1)	6.4 (6)	1.9	-0.29 – 9.8	0.06
Pre-CBT HoNOS-ABI (SD)[1]	12.4 (6.5)	12.4 (7)	115		0.87
Post-CBT HoNOS-ABI (SD)[1]	6.9 (5.5)	6 (4)	115		0.87
Dropped out or therapist stopped therapy*	34 (34.7)	22 (28.9)	0.66	-9 – 20	0.42
Female	23 (67.6)	10 (45.5)	2.65	-6.7 – 48	0.10
Male	11 (32.4)	12 (54.5)			
Single	14 (48.3)	15 (78.9)	4.4	-0.53 – 54.7	**0.04**
Married	15 (51.7)	4 (21.1)			
British	24 (70.6)	13 (59)	0.79	-15.5 – 38.5	0.38
Other ethnicity	10 (29.4)	9 (40.9)			
Employed	13 (39.4)	10 (45.5)	0.17	-24.6 – 35.7	0.68
Unemployed	20 (60.6)	12 (54.5)			
History of CSA	11 (36.7)	1 (5.9)	3.9	-3 – 51.1	**0.05**
No history of CSA	19 (63.3)	16 (94.1)			
Mean age at assessment (SD)[1]	41.7 (13)	40.3 (13)			0.74
Patient improved after CBT	8 (27.6)	7 (38.9)	0.64	-17.9 – 40.7	0.42
Patient worse/same after CBT	21 (72.4)	11 (61.1)			
Pre-CBT CORE-OM score (SD)[1]	17.4 (8)	15 (40	2		0.56
Post-CBT CORE-OM score (SD)[1]	9.4 (3)	13.1 (1)	0.5		0.14
Pre-CBT PHQ-9 score (SD)**	5 (5.7)	10	-	-	-
Post-CBT PHQ-9 score (SD)**	5 (7)	8	-	-	-
Pre-CBT HoNOS-ABI (SD)**	8.2 (4)	12	-	-	-
Post-CBT HoNOS-ABI (SD)**	8.6 (4)	13	-	-	-
Sessions ongoing	9 (9.2)	11 (14.5)	1.2	-5 – 16.4	0.28
Total	98 (100)	76 (100)			

[1] Mann-Whitney U test for non-parametric test

[2] Independent *t*-test

*Therapist stopped therapy in 6 F44.4 cases and 2 control group cases

** Only one available score, no comparisons made

Reasons for early therapy cessation were collected and compared between FMD and control groups. There was no available information in CRIS records on why patients had dropped out for 15 FMD patients (44.1%) and 14 control patients (63.6%).

In five cases (14.7%), FMD patients dropped out because they believed a physical cause accounted for their symptoms. In three cases in both the FMD and control group, participants believed therapy was not helpful or was making them worse. Three FMD patients dropped out because they felt the clinic was too far away and two developed a physical health problem while receiving treatment. In one case an FMD patient became too busy, another disengaged from therapy, one was unhappy with the CBT service generally, and another participant found CBT distressing. No statistical differences in reasons for CBT dropout were observed between groups. See Table 103, ("Appendix 6.1: Reasons for early therapy cessation for F44.4 and control groups") for dropout reasons.

6.3.8 CBT treatment length

The mean number of treatment sessions attended by FMD patients was 14.06 (SD: 8, range: 1 - 46) and for control group patients was 13.4 (SD: 7.3, 1- 40).

The mean number of treatment sessions missed by patients who dropped out was compared. The mean number of missed sessions was 2.44 (SD: 4.3) for FMD patients and 2.15 for the control group (SD: 3.8), with no statistical difference between the two groups. This suggests that patients had completed most of the treatment course before they dropped out.

Patients are assessed by a CBT therapist before they start treatment. The mean number of days between the assessment and the start of CBT treatment was 62.6 days (SD: 74.6) for FMD patients and 53.2 days (SD: 46.9) for control patients. There was no statistical difference between days.

The mean number of days between participants' first and last treatment session was 266 days (SD: 362) for FMD patients and 268 days (SD: 408) for control group patients.

The mean number of days between FMD patients' first treatment session and their last follow-up session was 390.2 days (SD: 277.7) and 414.1 days (SD: 297.7).

Table 104 in 'Appendix 6.2: Missed treatment sessions and mean days between appointments' outlines the mean number of missed treatment sessions and the mean number of days between assessments, treatments, and follow-up sessions for all other patients.

6.3.9 Therapy outcomes

This section outlines the response to treatment of FMD and control group patients.

Although therapy was on-going for nine FMD and eleven control patients at the time of data collection, they were included in our analysis as these participants had high attendance rates and they did not seem to differ greatly from other patients in the study. None had missed any CBT session and most had completed a high number of sessions. The mean number of attended sessions for FMD patients whose therapy was ongoing was 15.4 sessions (SD: 8), and for the control group it was 15.7 sessions (SD: 11.7).

For FMD patients with on-going sessions, two of the nine (22.2%) had symptoms that did not change, five had symptoms that improved (55.6%), and symptom improvement was unknown in two cases (22.2%).

For the control group, three patients' symptoms were worse (27.3%), two were the same (18.2%), three were better (27.3%), and in three cases, symptom improvement information was unknown (27.3%).

As this group of patients did not seem to differ greatly from other patients in the study, it was decided to include them in our subsequent analyses.

6.3.9.1 Target symptom

Based on information from clinical notes, the researcher classified patients' symptoms as either 'improved', the 'same' or 'worse'.

In total, 44 FMD patients (49.4%) and 40 control group patients (58%) improved, with no statistically significant difference between groups. Of FMD patients who improved, seven dropped out (15.9%), and in one case (2.3%) the therapist stopped the sessions early. In the control group, 6 patients (15%) whose symptoms had improved dropped out and in one case their therapist stopped the sessions (2.5%).

Eight FMD patients' (8.2%) and nine control group patients' (11.8%) symptoms were worse after CBT treatment. Thirty-seven (37.8%) FMD patients and 20 (20.4%) control group patients' symptoms remained the same after CBT.

Of patients whose symptoms were worse or the same after CBT treatment, 17 (37.8%) FMD and 10 (34.5%) control patients dropped out early while there were four FMD cases (8.9%) and one control case (3.4%) where the therapist decided to stop the treatment.

No information on patients' improvement was available for nine FMD patients (9.2%) and seven control patients (9.2%).

Patients whose symptoms were the same or worse were merged and data were stratified by socio-demographic variables. Comparisons were made between FMD and control groups according to gender, ethnicity, marital status, employment, receipt of welfare benefits, age, acceptance of psychological explanations prior to CBT, and health variables.

For patients who improved, no differences in socio-demographics emerged between groups, apart from gender. A higher proportion of female FMD patients improved compared to female control group patients ($\chi 2$: 9, 95% CI: 9.9 – 52.2, p = 0.003).

Patients whose symptoms stayed the same or got worse were compared but there were no differences between FMD and control groups on any of the measured socio-demographic variables.

Table 105 (see Appendix 6.3: Socio-demographic differences between F44.4 and control group patients according to their improvement) outlines the socio-demographic differences between FMD and control group patients who improved as well as comparisons between FMD and control groups for those patients who got worse or stayed the same.

A univariate analysis was conducted to examine FMD within-group differences. FMD patients who improved were compared to FMD patients who stayed the same or got worse according to socio-demographic variables. The variables assessed were gender, ethnicity, marital status, employment, carer status, benefits, wheelchair use, age, acceptance of a psychological explanation of symptoms prior to CBT, acceptance of a psychological explanation after CBT, experience of CSA or CPA as well as health variables.

Amongst FMD patients who improved, a higher proportion were in employment ($\chi 2$: 4, 95% CI: -1 – 40.1, p = 0.05), worked as health or social care workers ($\chi 2$: 4.3, 95% CI: -0.3 – 37.7, p = 0.04), accepted a psychological explanation for their symptoms both before ($\chi 2$: 7.7, 95% CI: 7.9 – 53.4, p = 0.006) and after CBT ($\chi 2$: 7.5, 95% CI: 5.6 – 43.2, p = 0.006), and had experienced CPA ($\chi 2$: 14.3, 95% CI: 19.6 – 62.4, p = 0.002) compared to those who stayed the same or got worse.

Amongst patients who got worse or stayed the same, a higher proportion received welfare benefits ($\chi 2$: 4.6, 95% CI: 0.43 – 41.8, p = 0.03) and they more frequently used a wheelchair or walking stick ($\chi 2$: 5.8, 95% CI: 3.5 – 47.2, p = 0.02) compared to patients who improved.

There were no differences in proportions between groups according to gender, ethnicity, marital status, employment rates pre-morbidity, patients with carers or patients who act as carers, age of psychiatric symptom onset, the age of CBT assessment, the experience of CSA, smoking status, family history of mental health disorders, or birth status.

Table 65 outlines the results of these within-group comparisons.

Table 65 Differences in socio-demographics between F44.4 patients who improved after CBT and F44.4 patients who got worse or stayed the same

		F44.4 group improved n (%)	F44.4 group worse, same* n (%)	χ^2	95% CI	*p* value
Total		44 (49.4)	45 (50.6)	0.03	-14 – 16.4	0.87
Gender	Female	32 (72.7)	33 (73.3)	0.004	-19 – 20.3	0.95
	Male	12 (27.3)	12 (26.7)			
Ethnicity	British	32 (72.7)	28 (62.2)	1.1	-10.4 – 30.4	0.29
	Other ethnicity	12 (27.3)	17 (37.8)			
Marital status	Single, divorced, widowed or separated	24 (54.5)	24 (53.3)	0.013	-20.5 – 22.8	0.91
	Married, civil partner or cohabiting	20 (45.5)	21 (46.7)			
Work	Employed	20 (45.5)	11 (25)	4	-1 – 40.1	**0.05**
	Unemployed, retired or sick leave	24 (54.5)	33 (75)			
	Employed pre-morbidly	39 (92.9)	42 (100)	3.01	-3.01 – 19.4	0.08
	Not employed pre-morbidly	3 (7.1)	0 (0)			
	Health/social care worker	14 (33.3)	6 (14)	4.3	-0.3 – 37.7	**0.04**
	Not a health/social care worker	28 (66.7)	37 (86)			
Carer	Patient is a family carer	5 (11.9)	5 (11.9)	0	-15.8 – 15.8	1
	Patient is not a family carer	37 (88.1)	37 (88.1)			
	Patient has a carer	8 (20)	13 (33.3)	1.8	-7.9 – 33.4	0.18
	Patient doesn't have a carer	32 (80)	26 (66.7)			
Benefits	Receives benefits	9 (22)	24 (44.2)	4.6	0.43- 41.8	**0.03**
	Does not receive benefits	32 (78)	19 (55.8)			
Disability	Uses wheelchair or walking aid	15 (36.6)	26 (63.4)	5.8	3.5 – 47.2	**0.02**
	Doesn't use wheelchair	26 (63.4)	15 (36.6)			
Age	Mean age at psych symptom onset (SD)[1]	31.4 (16)	29 (11)	- 0.8	-8.4 – 3.6	0.43
	Mean age at assessment[1] (SD)	40.6 (15)	39.5 (11)	-0.38	-6.7 – 4.5	0.70
Psych factors	Accepted psych factors before	26 (81.3)	17 (48.6)	7.7	7.9 – 53.4	**0.006**
	Didn't accept psych factors before	6 (18.8)	18 (51.4)			
	Accepts psych role after	37 (92.5)	25 (67.6)	7.5	5.6 – 43.2	**0.006**
	Didn't psych role after	3 (7.5)	12 (32.4)			
Abuse	Experienced CSA	8 (23.5)	8 (20.5)	0.09	-17.4 – 23.9	0.76
	Didn't experience CSA	26 (76.5)	31 (79.5)			
	Experienced CPA	13 (63.9)	8 (20.5)	14.3	19.6 – 62.4	**0.002**
	Didn't experience CPA	23 (36.1)	31 (79.5)			
Health	Smokes	11 (32.4)	14 (43.8)	0.89	-13.8 – 35.3	0.34
	Does not smoke	23 (67.6)	18 (56.3)			
	Family mental health history	24 (66.7)	22 (64.7)	0.03	-21.5 – 24.5	0.86
	Not family mental health history	12 (33.3)	12 (35.3)			
	Normal birth and delivery	19 (82.6)	18 (90)	0.48	-17.6 – 30.5	0.49
	Problems during birth	4 (17.4)	2 (10)			

*Eight F44.4 patients got worse and nine control patients got worse

[1] Independent samples *t*-test

Based on the univariate analysis, variables that showed a significant association with symptom improvement were chosen for inclusion in a binary logistic regression analysis. These variables included acceptance of psychological explanations before and after CBT, experience of childhood physical abuse, receipt of benefits, working as a social or healthcare worker, employment status and use of a wheelchair or walking aid. The model explained 41.7% (Nagelkerke R Square) of the variance seen in symptom improvement but no variables significantly predicted symptom improvement.

6.3.9.2 CORE-OM scores pre- and post-treatment

Patients' CORE-OM scores were taken prior to CBT and after its conclusion.

Pre-CBT CORE-OM scores were those taken within 180 days of the CBT assessment date or first treatment session. Post-CBT CORE-OM scores were those taken within 180 days of the last day of treatment or the last follow-up appointment. Due to a general lack of available outcome measures, this relatively wide time range was used for inclusion of scores.

Of the 24 FMD patients with CORE-OM scores at both the pre- and post-CBT stage, 20 FMD patients completed all their CBT sessions, three had dropped out early and one still had on-going sessions. Of control group participants, 22 had completed all of their CBT sessions while two dropped out early.

An analysis was conducted to assess whether there were any significant differences in socio-demographics between FMD patients who had CORE-OM scores versus those who did not. No differences were found (see Table 106, 'Appendix 6.4: Socio-demographic differences between patients with clinical outcome scores and those with one or none').

Of patients with two CORE-OM scores, a repeated measures *t*-test showed FMD patients' scores dropped from a moderate mean of 15.5 (SD: 6.2) to a clinically low mean of 10 (SD: 6.6) (t = 3.9, df = 23, 95% CI: 2.6 – 8.3, two-tailed p = 0.001). Control group patients' scores also dropped from a mean of 16.3 (SD: 6.8) (considered a moderate score) to a mean of 12.8 (SD: 6.6) (considered clinically mild), denoting a statistically significant drop (t = 2.9, df = 23, 95% CI: 1.06 – 5.9, two-tailed p =0.007).

Table 66 shows the mean scores of both patient groups before and after CBT treatment and stratified by socio-demographic variables. Any variables with less than ten participants, after stratification were removed and are not reported here.

Table 66 Pre- and post-treatment clinical mean CORE-OM score for F44.4 and control group

		Mean first clinical CORE-OM score (SD)	Mean last clinical CORE-OM score(SD)	Mean diff	*t* test	*p* value	*d*
F44.4 Group (Total participants = 24)		15.5 (6.2)	10 (6.6)	5.4	3.9	**0.001**	0.86
Gender	Female (Total = 18)	14.9 (6.7)	9.2 (5.7)	5.7	3.5	**0.003**	0.82
Ethnicity	British (Total = 16)	16.2 (6)	10 (7)	6.3	3.4	**0.004**	0.85
Marital status	Single (Total = 10)	14.6 (8)	10.3 (7)	4.2	1.9	0.10	0.71
	Married (Total = 11)	15.4 (5)	10.2 (8)	5.1	2.5	**0.03**	0.80
Work	Employed (Total = 11)	14.4 (7)	6 (5)	8.4	3.7	**0.004**	1.08
	Unemployed (Total = 13)	16.3 (6)	13.4 (6)	2.9	2.1	0.056	0.58
Role of psych factors	Accepted psych factors pre-CBT (Total = 12)	15.9 (7)	8.9 (7)	7	3.1	**0.01**	0.87
	Accepted psych factors post-CBT (Total = 15)	15.7 (7)	9.6 (7)	6.1	3.2	**0.007**	0.78
Carer	Patient doesn't have carer (Total = 18)	15.2 (6)	9.4 (7)	5.9	3.4	**0.004**	0.78
Disability	Uses wheelchair or other walking aid (Total = 8)	17.2 (5)	9.7 (6)	7.5	2.8	**0.03**	0.98
	No wheelchair/walking aid (Total = 15)	14.5 (7)	10.8 (7)	3.6	2.5	**0.03**	0.64
Abuse	No history of CPA (Total = 15)	14.5 (6)	9.4 (6)	5.0	3.4	**0.004**	0.89
Health	History of familial mental health problems (Total = 15)	15.5 (7)	10.5 (7)	5.0	3.0	**0.01**	0.76
	Does not smoke (Total = 10)	13 (7)	8.9 (7)	4.0	2.1	0.08	0.66
Control Group (Total participants = 24)		16.3 (6.8)	12.8 (6.6)	3.5	2.9	**0.007**	0.92
Gender	Male (Total = 15)	15.1 (7.6)	12.9 (7)	2.2	1.4	0.19	0.35
Marital status	Single (Total = 16)	15.9 (7)	13 (6)	2.9	1.8	0.10	0.48
Ethnicity	British (Total = 19)	15.5 (6)	11.6 (6)	3.9	2.8	**0.01**	0.67
Work	Employed (Total = 13)	13.9 (5)	10.5 (6)	3.4	2.4	**0.04**	0.64
Carer	Patient doesn't have carer (Total = 17)	14.4 (6)	11.5 (7)	2.9	2.4	**0.03**	0.59

Scores range from 0-40: Healthy (0-5); low level (5-10); mild (10-15); moderate (15-20); moderate-to-severe (20-25); severe (25 -40)

*****Participants' first CORE-OM score included if within 6 months of assessment or first treatment date & second CORE-OM score included if within 6 months of the final treatment or follow-up session.

Data were stratified by socio-demographic variables. Within the FMD group, there were significant improvements for female (t = 3.5, df = 17, 95% CI: 2.2 – 9.2, p = 0.003), British (t = 3.4, df = 15, 95% CI: 2.3 – 10.2, p = 0.004), married (t = 2.5, df = 10, 95% CI: 0.56 – 9.7, p = 0.03), and employed patients (t = 3.7, df = 10, 95% CI: 3.3 – 13.5, p = 0.004), patients who accepted psychological explanations before (t = 3.1, df = 11, 95% CI: 2 – 11.9, p = 0.01) and after CBT treatment (t = 3.2, df = 14, 95% CI: 1.9 – 10.2, p = 0.007), those who did not have a carer (t = 3.4, df = 17, 95% CI: 2.2 – 9.5, p = 0.004), patients who both used (t = 2.8, df = 7, 95% CI: 1.2 – 13.8, p = 0.03) and did not use a wheelchair or walking aid (t = 2.5, df = 14, 95% CI: 0.5 – 6.8, p = 0.03), those with no history of CPA (t = 3.4, df = 14, 95% CI: 1.8 – 8.2, p = 0.004) and patients with a history of family mental health problems (t = 3, df = 14, 95% CI: 1.5 – 8.6, p = 0.01).

Figure 35 displays a paired dotted line graph of individual patients' scores before and after CBT treatment in the FMD and control groups.

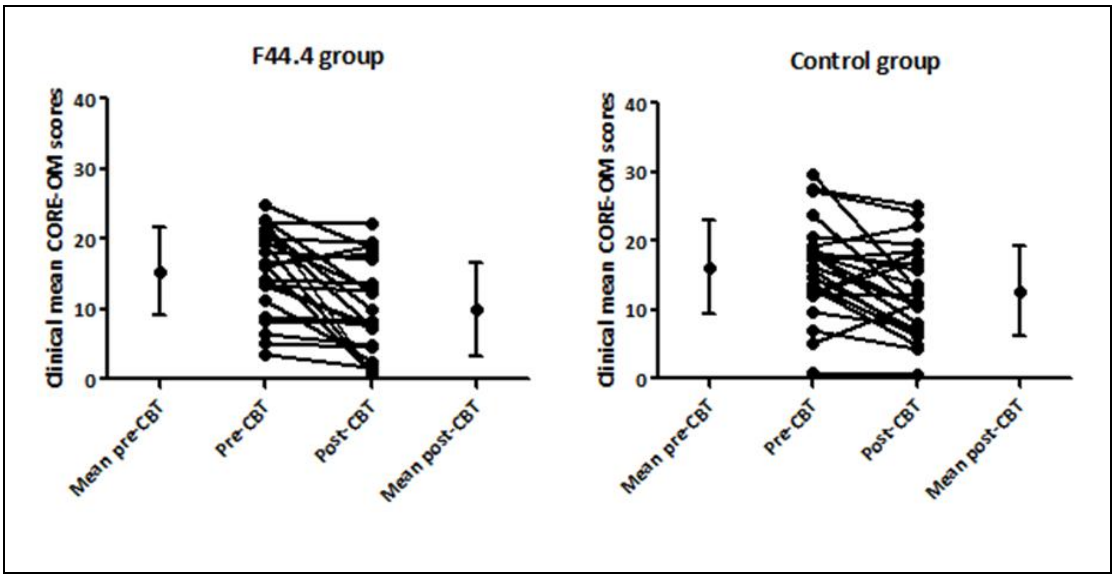

Figure 35 Paired dotted line graphs showing change in clinical mean CORE-OM scores for the functional and control groups at the start and end of treatment

To assess treatment outcomes, we conducted a repeated-measures (pre-CBT versus post-CBT) ANOVA, with patient group (FMD versus control) as a fixed factor. The Bonferroni-corrected interaction between the FMD and control groups and the change over time (pre- versus post-CBT) was not statistically significant ($F_{1,46} = 1.13$, $p = 0.30$, partial $\eta^2 = 0.02$). The pre-CBT scores between the FMD and control groups did not differ significantly, and there was no significant difference in post-CBT scores between groups. Figure 36 displays a line graph showing the change in overall mean CORE-OM scores between the FMD and control groups.

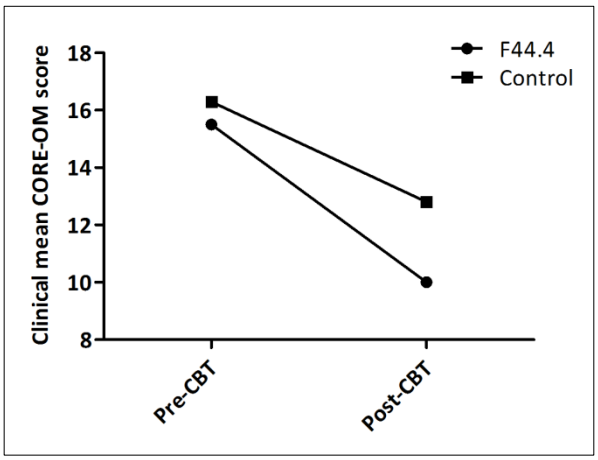

Figure 36 Line graph demonstrating change in overall mean CORE-OM scores between F44.4 and control groups pre- and post-CBT

Further sub-group analyses within FMD patients were conducted using a repeated measures ANOVA (see "Appendix 6.5: CORE-OM mean clinical score sub-analysis: repeated measures ANOVA"). The interaction between the change in FMD patients' CORE-OM mean clinical scores over time and the socio-demographic variables listed in Table 66 (e.g. gender, ethnicity, etc.) was tested for statistical significance.

The only interaction of statistical significance was that of FMD patients' CORE-OM scores and employment status ($F_{1, 22}$ = 4.6, p = 0.04, partial η^2 = 0.17). FMD participants who were employed saw a significant drop in their CORE-OM clinical mean scores (t = 3.7, df = 10, two-tailed p = 0.004) while there was no significant difference for unemployed participants (t = 2.1, df = 12, two-tailed p = 0.056).

6.3.9.3 HoNOS scores pre- and post-treatment

Four FMD and five control patients had a HoNOS score within 180 days of their assessment or first day of treatment and within 180 days of their final treatment session or follow-up appointment. The small numbers limited the number of statistical tests used in this study.

FMD patients' HoNOS scores got slightly worse over time with a mean of 7.25 (SD: 2.4) at the start of treatment increasing to a mean of 8 (SD: 3.3) after treatment, though the change was not statistically significant (Z = -0.37, p= 0.72). Control group participants saw their scores improve over time from a mean of 9.6 (SD: 1.2) to 5.8 (SD: 1.9) and this change was also not statistically significant (Z = -1.5, p = 0.14).

Given the small sample size, no further stratification or analyses were conducted. Table 67 shows the breakdown of HoNOS scores before and after therapy.

Table 67 HoNOS scores for F44.4 and control group participants

	First HoNOS mean score (SD)	Last HoNOS mean score (SD)	Mean diff	Wilcoxon signed ranks	*p* value
F44.4 group (Total participants = 4)	7.25 (2.4)	8 (3.3)	- 0.8	- 0.37	0.72
Control group (Total participants = 5)	9.6 (1.2)	5.8 (1.9)	3.8	-1.5	0.14

Range: 0 (best) - 48 (worst outcome)

6.3.9.4 HoNOS-ABI scores pre and post-treatment

In total, 22 FMD patients had HoNOS-ABI scores available before and after CBT treatment and 20 control patients had scores at both time periods.

Of the FMD patients, 17 had attended all the treatment sessions, four dropped out early, and in one case, the therapist stopped the session. Data were available for 15 control group participants of whom 14 had attended all their treatment sessions while one dropped out early. There were no significant socio-demographic or health differences between patients who had two available HoNOS-ABI scores and those with one or no available score (see Table 107, "Appendix 6.4: Socio-demographic differences between patients with clinical outcome scores and those with one or none").

The mean HoNOS-ABI score for FMD patients prior to the start of CBT was 11.5 (SD: 6) and after therapy it dropped to 7.3 (SD: 5) representing a significant change (Z = -3.1, p = 0.002). The mean pre-CBT score for control patients was 12.3 (SD: 7), and post-CBT it was 6.5 (SD: 4), a significant drop in mean scores (Z = -3, p = 0.003). Control group variables, when stratified by socio-demographics, contained less than five participants in each group so sub-group analyses were not conducted.

Table 68 outlines HoNOS-ABI scores and scores after stratification by socio-demographic variables.

Table 68 HoNOS-ABI scores and potential confounding variables for F44.4 and control groups

		First HoNOS -ABI score (SD)	Last HoNOS -ABI score (SD)	Mean diff	Wilcoxon signed-ranks (*z*)	*p* value	*d*
F44.4 group (Total participants = 22)		11.5 (6)	7.3 (5)	4.2	-3.1	**0.002**	0.76
Gender	Female (Total = 15)	11.3 (7)	6.2 (4)	5.1	-2.8	**0.005**	0.89
Ethnicity	British (Total = 12)	13.5 (6)	6.8 (4)	6.7	-2.6	**0.009**	1.31
	Other ethnicity (Total = 10)	9 (5)	7.8 (7)	1.2	-1.6	0.10	0.19
Marital status	Single (Total = 10)	12.1 (7)	7.1 (5)	5	-2.2	**0.03**	0.82
Work	Unemployed (Total =13)	13.1 (7)	8.6 (6)	4.9	-2.1	0.03	0.69
Psych factors	Accepted psychological explanation pre-CBT (Total = 10)	11.8 (7)	7.5 (7)	4.3	-2.2	**0.003**	0.61
	Accepted psychological explanation post-CBT (Total = 12)	12.8 (8)	6.8 (6)	6.0	-2.5	**0.012**	0.85
Carer	Patient does not have carer (Total = 13)	11.2 (6)	5.7 (3)	5.5	-2.8	**0.005**	1.16
Abuse	Did not experience CPA (Total = 12)	9.9 (6)	6.9 (6)	3	-2.1	**0.04**	0.5
Disability	Uses walking aid (Total = 11)	12.7 (7)	6.4 (4)	6.3	-2.6	**0.01**	1.1
Health	Family mental health history (Total = 10)	11.6 (7)	7.1 (4)	4.5	-2.4	**0.02**	0.79
	Does not smoke (Total = 8)	8.6 (6)	4.9 (3)	3.7	-2.0	**0.04**	0.78
Control group (Total participants = 15)		12.3 (7)	6.5 (4)	5.8	-3.0	**0.003**	1.01

Scores range from 0 to 48 (most severe)

Like the CORE-OM scores, there were significant within-group differences in both the FMD (Wilcoxon signed ranks = -3.1, p = 0.002) and control groups (Wilcoxon signed ranks = -3.0, p = 0.003) over time according to socio-demographic variables. FMD patients who were female,

British, single, who accepted a psychological explanation before CBT, who accepted a psychological explanation after CBT, patients without a carer, those who did not experience childhood physical abuse, those who used a walking aid, those with a family history of mental health problems and those who did not smoke saw significant decreases in their HoNOS-ABI scores. In many variables are missing here as they contained less than five participants.

Figure 37 displays a paired dotted line graph showing the change in scores over time for both the FMD and control group.

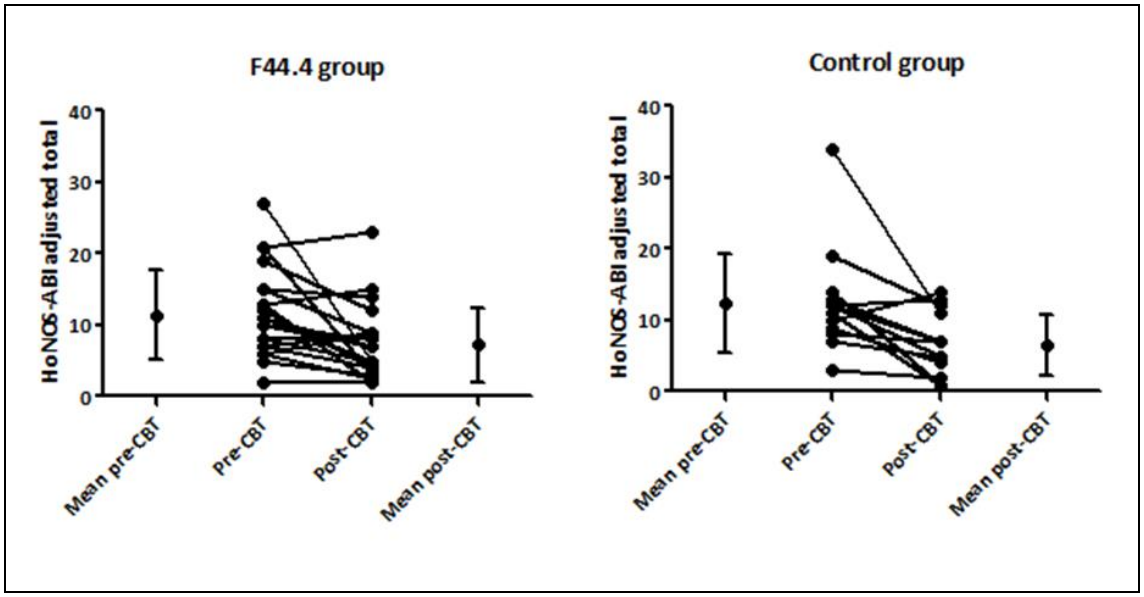

Figure 37 Paired dotted graph showing each participants' change in HoNOS-ABI scores pre- and post-CBT

Similarly to the CORE-OM clinical score results, a two-way repeated measures ANOVA found no significant interaction between the FMD and control groups and changes in pre- and post-CBT HoNOS-ABI scores ($F_{1,35} = 0.58$, $p = 0.45$, partial $\eta^2 = 0.02$).

The mean scores are shown in a line graph in Figure 38.

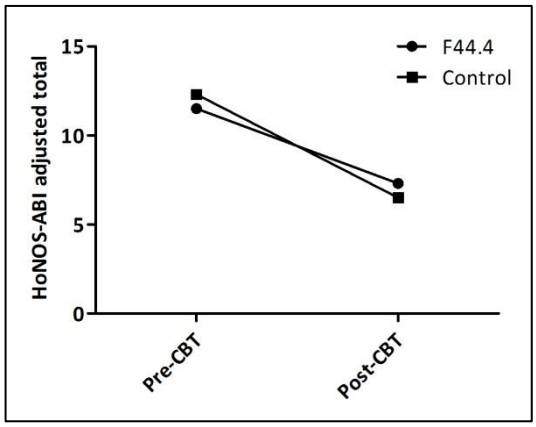

Figure 38 Figure showing change in mean HoNOS-ABI scores between F44.4 and control groups before and after CBT treatment

Interaction effects were explored within FMD patients according to socio-demographic variables (see "Appendix 6.6: Mean adjusted HoNOS-ABI sub-analysis: repeated measures ANOVA"). There was a significant interaction between change in FMD patients' HoNOS-ABI scores and ethnicity ($F_{1,20}$ = 5.3, p = 0.03, partial η^2 = 0.21), but no other significant interaction was found.

6.3.9.5 PHQ-9 scores pre and post CBT treatment

Pre-CBT PHQ-9 scores were collected if they were within 180 days of the patient's assessment date or their first day of CBT treatment. Post-CBT PHQ-9 scores were those within 180 days of the patient's last date of treatment or last follow-up session.

PHQ-9 data were available for 16 FMD patients and ten control patients. Of FMD patients with available PHQ-9 scores, 13 had attended all sessions, two dropped out early and one participant still had some sessions to complete.

Table 108 ("Appendix 6.4: Socio-demographic differences between patients with clinical outcome scores and those with one or none") outlines the characteristics of FMD patients with two available PHQ-9 scores versus patients with one or no available PHQ-9 scores. There were no differences in socio-demographics between these groups of FMD patients, although patients with two PHQ-9 scores were more likely to be single than patients with one or no available PHQ-9 score (χ^2: 4.2, 95% CI: -1.9 – 52.9, $p < 0.05$).

The mean PHQ-9 score for FMD patients prior to the start of CBT was 13.5 (SD: 7). Post CBT, there was a statistically significant drop to 9.9 (SD: 6) (t = 2.6, df = 15, 95% CI: 0.6 – 6.5, two-

tailed p = 0.02). Due to the small sample size, no stratified analyses w conducted for the control group.

See Table 69 for a full breakdown of PHQ-9 scores before and after CBT according to socio-demographic variables.

Table 69 Mean total PHQ-9 scores before and after CBT treatment for F44.4 and control groups by socio-demographic factors

	Mean total PHQ-9 pre-CBT (SD)	Mean total PHQ-9 post-CBT (SD)	Mean diff	*t*-test	95% CI	*p* value
F44.4 group (Total participants = 16)	13.5 (7)	9.9 (6)	3.6	2.6	0.6 – 6.5	**0.02**
Female (Total = 14)	13.1 (7)	9.3 (6)	3.8	2.4	0.4 – 7	**0.03**
Unemployed (Total = 11)	16.1 (6)	11.8 (5)	4.3	2.4	0.4 – 8.2	**0.04**
Doesn't receive benefits (Total = 10)	13 (8)	9.1 (6)	3.9	2.2	-0.1 – 7.9	0.06
Patient does not have carer (Total = 11)	11.8 (6)	8.8 (5)	3	1.8	-0.6 – 6.6	0.10
Single (Total = 10)	11.2 (7)	8.9 (5)	2.3	1.3	-1.8 – 6.4	0.24
Didn't experience CSA (Total = 10)	12.4 (6)	8.1 (6)	4.3	2.4	0.2 – 8.4	**0.04**

Scoring guide: '0-4' no depression; '5-9' mild; '10-14' moderate; '15-19' moderately severe; '20-27' severe

Within-group FMD differences were explored by socio-demographic variables. FMD patients who were female (t = 2.4, df = 13, 95% CI: 0.4-7, two-tailed p = 0.03), unemployed (t = 2.4, df = 10, 95% CI: 0.4 – 8.2, two-tailed p = 0.04), and those that did not experience CSA (t = 2.4, df = 9, 95% CI: 0.2 – 8.4, two-tailed p = 0.04) saw a significant decrease in their mean score between the beginning and end of CBT.

Figure 39 displays the paired dotted line graph showing change in PHQ-9 scores over time in the FMD and control groups.

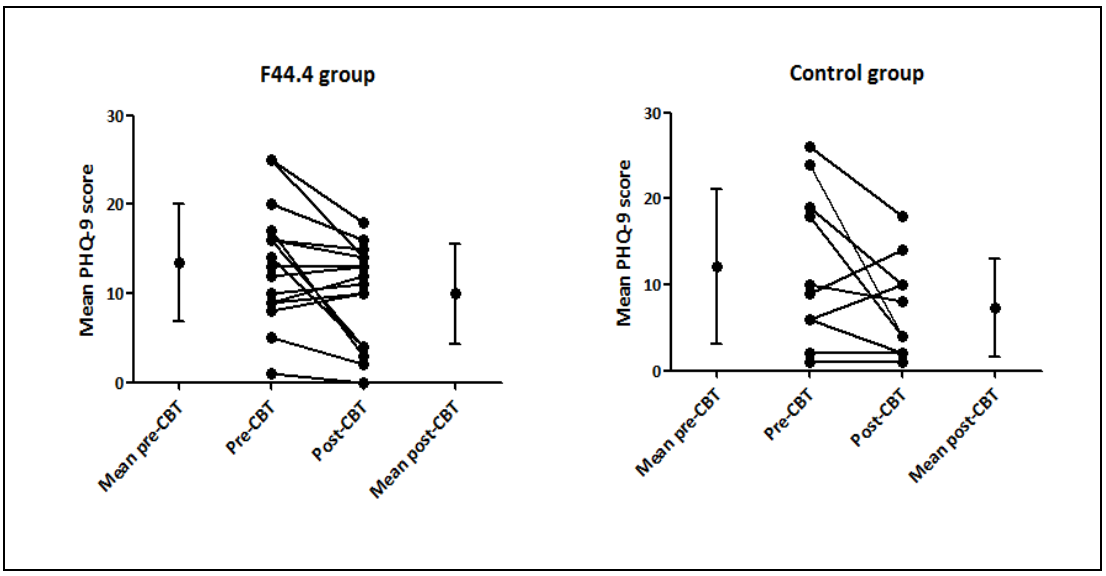

Figure 39 Paired dotted graph showing each participants' change in PHQ-9 scores pre- and post-CBT

Using a repeated-measures two-way ANOVA, the interaction between the FMD and control groups and the change over time between the pre-and post-CBT assessment was examined. This was not statistically significant ($F_{1,24} = 0.22$, $p = 0.64$, partial $\eta^2 = 0.01$). Mean PHQ-9 scores between groups are displayed at pre- and post-treatment in Figure 40.

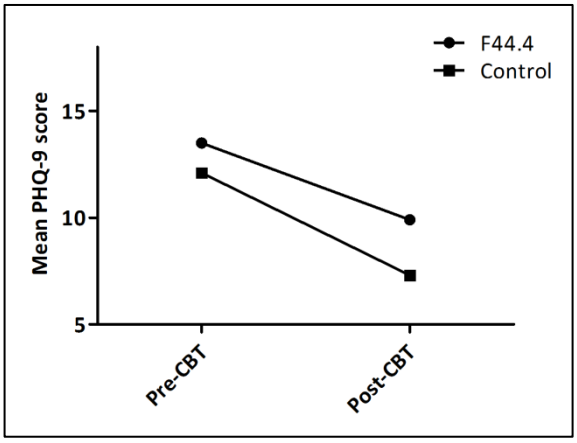

Figure 40 Figure showing change in mean PHQ-9 scores between F44.4 and control groups before and after CBT treatment

Repeated measure two-way ANOVAs were conducted to assess interactions within the FMD group according to socio-demographic variables. No significant interactions were found (see "Appendix 6.7: Mean PHQ-9 scores sub-analyses: Repeated measures ANOVA").

6.4 Discussion

6.4.1 Main findings

In our study, half of FMD patients (49.4%) saw improvements in symptoms from the beginning to the end of CBT therapy. 41.6% of FMD patients' symptoms remained the same and 9% of cases got worse, comparable to the 10.1% of control group patients with neurological disease whose symptoms also worsened. FMD patients improved as a response to CBT treatment according to the clinical outcomes measures available. FMD patients' mean CORE-OM, HoNOS-ABI and PHQ-9 scores all saw clinically significant reductions indicating improvement in psychological distress, depression, and physical functioning. Control patients also had significant improvements in scores. There were no significant interactions between FMD and control groups and pre- and post-therapy clinical scores, indicating that CBT is effective for both groups.

Regarding socio-demographic, and health outcomes, and experience of traumatic events, no differences emerged in ethnicity, marital status, housing, age or benefits between groups. FMD patients were however more likely to be female, unemployed, to be a carer and to have a carer, to have experienced CSA but were less likely to have a comorbid physical health condition. FMD patients had lower rates of anxiety but higher rates of fatigue compared to the control group.

While only half the FMD group experienced improvements in symptoms may seem disappointing, these findings should be viewed within the context of previous literature on prognosis in FND.

A systematic review of 22 studies on prognosis in patients with functional motor symptoms by Gelauff et al. (2014) found 39% of patients had the same or worse symptoms at follow-up (11.6% less than in our study), but only 20% of patients had complete symptom remission. Their review included a number of studies which assessed treatment outcomes. The treatments included in the review were heterogeneous but, of these studies, the proportion of patients who were the same or worse was 49%, analogous to our result. The mean follow-up of 7.4 years in their review makes definitive comparisons difficult.

Speckens et al. (1995) reported results from an RCT testing CBT on patients with medically unexplained physical symptoms. They reported a 6-month post-treatment improvement of 64% in the intervention group, with 18% remaining the same. At 12-month follow-up however, improvement had dropped to 51%, and 27% were the same or worse, suggesting improvements in the longer term may be harder to sustain. Important factors linked to these

findings include the person conducting the therapy sessions. Previous research suggests GPs using CBT are no more effective than treatment as usual (Arnold et al., 2009; Sumathipala et al., 2008). Specken's study took place in a general medical outpatient clinic and the attending physician was involved in the initial treatment session. The authors argue that the lack of a psychological referral was important to participants a factor which may have affected treatment dropout in our findings.

Two caveats are worth noting when comparing our findings to previous CBT trials. Our study comprises results from a naturalistic study without the artificial selection criteria often applied in RCTs. Our results highlight the practicalities of delivering CBT in the community and our findings are closer in comparison to a pragmatic RCT measuring effectiveness than to one assessing pure efficacy. Our method may mean our results have increased generalisability. Secondly, most of the RCTs outlined above do not list the reasons why patients refused to participate. The method we adopted means we have a relatively good degree of information on the reasons patients did not take up CBT when offered and why they dropped out, results pertinent to future service planning. Our analytic approach is similar to an intention-to-treat analysis often used in RCT studies whereby patients are included in the analysis even if they had dropped out.

LaFrance et al.'s (2009) study of CBT reported a reduction of NES frequency of 50% in 16 patients (76.2%). They also reported improvements in depression, anxiety, family life, and psychosocial functioning. CBT's effectiveness in improving psycho-social symptoms is well established, a fact again confirmed in a large RCT testing CBT on patients with health anxiety in medical clinics (Tyrer et al., 2014). CBT may therefore be particularly effective in reducing the underlying psychological factors that cause or worsen physical symptoms.

CBT has been shown to be effective in reducing the psychological symptoms associated with FND or unexplained symptoms. However, Kroenke and Swindle (2000) concluded that reductions in physical complaints can occur independently of psychological distress reduction. Our study found reductions in both physical symptoms and psychological distress. While our clinical scores capture a proportion of participants' fluctuations in psychological distress, our symptom improvement measures may be overly prescriptive. The goals of CBT are often not simply somatic symptom reduction, but initially are often aimed at improving the thinking and behaviour associated with symptoms. Commonly, patients themselves discuss their goals at the start of treatment. Had our symptom improvement score measured a more global measure of improvement or included patients' achievement of individual personal goals set at the start of therapy, it is possible that a higher proportion of patients would have been

classified as 'improved'. The use of medical records, rather than face-to-face contact limited the type and range of measures that we could employ, an issue discussed in more detail in Section 6.4.2 of this discussion.

The socio-demographic findings in our study are broadly similar to Chapter Five's findings. The same rate of gender was found. Our rate of 72.4% females is similar but lower than the 78.8% rate reported by McCormack et al. (2014) in an inpatient specialist unit in SLaM, perhaps reflecting a higher rate of severity in the inpatient setting. Similar rates of ethnicity, marital status and housing status were found amongst FMD patients in this study and FMD patients in Chapter Five. In this study however, no FMD patient was homeless and fewer lived in sheltered or supported accommodation. A higher proportion of patients in this study were employed compared to FMD patients in Chapter Five. Sexual abuse rates in childhood were broadly similar (23.8% versus 20% in Chapter Five) but childhood physical abuse was somewhat higher in this study (28.4% versus 22.7%). Age rates in both studies were similar. Similar to findings in Chapter Five, the most frequent symptom amongst FMD patients was weakness. Equal proportions of FMD patients had symptoms defined as 'abnormal' and 'loss' but our finding differs from McCormack et al.'s inpatient results where the majority of their patients reported symptoms defined by loss of motor function.

The similarities in socio-demographics can be partly explained as many of the patients who feature in this study are also included in Chapter Five. The differences between FMD groups in employment and accommodation rates are not surprising. Being homeless, unemployed or having precarious or unstable living conditions will likely make regular attendance in outpatient CBT more problematic and these patients may be less likely to be offered a treatment course in general. The higher rates of abuse observed in this study may be linked to a referral bias whereby patients who experienced abuse in childhood likely have higher symptom morbidity, and are more likely to receive a CBT referral.

6.4.1.1 Prognostic factors

A number of socio-demographic characteristics emerged in the comparison of FMD patients whose symptoms improved compared to those who stayed the same.

Our univariate analyses found that a significantly higher proportion of FMD patients who got worse or stayed the same received welfare benefits compared to those patients who improved. FMD patients who received benefits at the time of admission to a tertiary referral hospital were more likely to have poorer outcomes (Crimlisk et al., 1998) and the same finding was reported in neurology outpatient settings (Sharpe et al., 2010). Receipt of benefits may be

a proxy measure for socio-economic status. Patients in lower SES categories may have more difficulty in overcoming the social and psychological barriers linked to symptom remission but another explanation is that receiving benefits may reflect more ingrained illness beliefs, secondary gain or increased disability which in themselves may explain a poorer prognosis.

Our findings show a higher percentage of patients whose symptoms improved were employed, and a positive interaction in CORE-OM scores was found in FMD patients who were employed versus FMD patients who were unemployed. This finding has also been reported in NES patients (McKenzie et al., 2010; Reuber et al., 2003). Moreover, our study found a higher proportion of patients who improved worked or had worked as health or social care workers. As discussed previously, working in health or social care has been highlighted as a feature amongst FND patients, but to our knowledge has not previously been considered a positive prognostic factor. Being a clinical worker may be an advantage to participants as they may be more likely to have previously been exposed to the language and themes of CBT and recovery prior to their referral, aiding recovery. Alternatively, the positive effect of health and social care work may be explained entirely by employment itself.

Of patients whose symptoms stayed the same or got worse, a higher proportion used a walking aid than those FMD patients who improved. This finding likely reflects pre-treatment severity whereby these patients' with mobility aids had more severe or chronic symptoms at the start of CBT compared to those patients who improved as a result of CBT. While we did not measure whether there was any change in use of walking aids as a result of CBT, McCormack et al. (2014) reported that following specialist neuropsychiatry inpatient treatment, wheelchair usage fell by 42.4%. Such a measure was not possible in our study as wheelchair usage was uncommon across the FMD group.

Our findings suggest that accepting a psychological account of symptoms both before and after CBT predicts greater symptom improvement, a finding reported previously. Sharpe et al. (2010) found that a strong independent predictor of poorer outcomes after one year was the non-attribution of symptoms to psychological factors. Another study reported that belief in stress or an 'emotional state' as the cause of functional motor symptoms was associated with greater improvements after admission to an inpatient rehabilitation programme (Saifee et al., 2012). These findings are mildly tautological as a cornerstone of CBT is often the re-attribution of symptoms and the restructuring of illness beliefs. What is particularly interesting however are the three FMD patients (7.5%) in our study who did not accept a psychological explanation but nonetheless saw improvements in physical symptoms. While Saifee et al. (2012) argue that patients' psychological attributions could potentially be used as a selection criterion for

acceptance to treatment programmes, our findings suggest, for a small proportion of patients, improvement may be possible without accepting a psychological account.

Our study found no prognostic effect of marital status, a result also reported in Feinstein et al.'s (2001) study. Crimlisk et al. (1998) suggest however that a change in marital status and the leaving of an unhappy relationship is associated with better prognosis, a process we did not measure.

In our study gender did not play a role in FMD patients' improvement. Research on prognosis and gender has mixed results. Czarnecki et al. (2012) found females in their study had a higher rate of recovery compared to males, while other research found no influence of gender on outcomes (Binzer & Kullgren, 1998; Crimlisk et al., 1998; Ibrahim et al., 2009; Thomas et al., 2006). The over-representativeness of females in our study, and in most FND research, make conclusions on the prognostic value of gender difficult to draw.

Age of symptom onset is often reported in FND literature as a prognostic factor, with a higher age of onset linked to poorer prognosis (Moene et al., 2000; Stone et al., 2003). No difference in age of onset was found in our study between those who improved and those who stayed the same or got worse. Nevertheless, the long delay we observed between symptom onset and the offer of treatment is a general concern for NHS services.

While the variables outlined above were statistically significant in our univariate analyses, our multivariate logistic regression analysis results did not find a positive association when these prognostic factors were considered at once. It is therefore likely that welfare benefits, employment, pre-morbid employment, wheelchair use, ethnicity, gender, and psychological acceptance are covariates. Studies with larger samples are needed to establish robust theoretical, causative and prognostic models.

6.4.1.2 Patient dropout

Engagement is an important part of the CBT process (Kent and McMillan, 2009). Therapists and commissioners invest time and resources in reducing dropout and missed appointments. In the neuropsychiatry CBT clinic, patients are selectively chosen based on presumptions about their ability to engage in therapy. Clinicians will discharge patients if a patient has missed an appointment more than once, without giving prior warning to their clinician. After the first missed appointment they will receive a reminder letter from the clinic warning of the possibility of discharge and the cost of non-attendance to the service.

Predictors of adherence to treatment are relatively under-studied in FND generally. Patients referred to an FND clinic from the emergency department are less likely to attend their initial outpatient consultation compared to patients from other settings (Perez et al., 2016). Glass et al. (2017) reported FND patients on antidepressant medication at baseline, or those with Generalised Anxiety Disorder, were less likely to miss an outpatient follow-up visit, arguing that these factors may signify an existing willingness to engage in interdisciplinary treatment. They also found that patients with functional weakness were more likely to be at risk of treatment nonadherence compared to other types of FND, suggesting that this may be explained by gender and psychopathology (Glass et al., 2017). A recent paper following patients with NES for over a year and a half reported 80% attended their first outpatient psychiatric appointment, but only 14% attended their fourth and final appointment (Tolchin et al., 2017). The authors found lower scores on the Brief-IPQ (indicating less concern about the illness) predicted greater nonadherence.

Of the 200 FMD patients in our study who were offered a CBT assessment appointment, only 49% went on to receive treatment. The relatively low rate of CBT uptake is partly explained by patients receiving a more appropriate inpatient referral to the Lishman Unit. The lower uptake may also be partly explained by the national referral status of the clinic as patients may have to travel longer distances to attend sessions which may be particularly problematic in the case of patients with motor deficits. The acceptability of CBT to the patient will play a role in treatment uptake. A higher proportion of FMD compared to control patients in our study refused treatment after their assessment. It is possible that the psychological-nature of the therapy did not align with their illness beliefs although once CBT began, no difference in dropout rates emerged between patient groups.

Clinicians offer CBT to patients they believe will engage in and respond to treatment and patients who oppose a psychosocial explanation will likely self-select out of CBT. Despite the likely selection bias, the CBT treatment dropout rate of 34.7% for FMD patients is reasonably high. Wierzbicki and Pekarik (1993) assessed psychotherapy dropout in a meta-analysis and reported a rate of 46.9%. A recent meta-analysis reported the dropout of patients with a spectrum of psychological disorders from CBT was lower, at 26.2% (Fernandez et al., 2015). Depression, and outpatient rather than inpatient settings were associated with higher rates of CBT attrition. It is likely that patients with somatoform disorder have higher rates of dropout generally, with previous reports of dropout for these patients ranging from 21-50% (Crane et al., 2012). Our rate falls within this range.

We investigated the socio-demographic variables linked to treatment dropout. Patients who stopped treatment early had a higher rate of CSA. Patients with experiences of CSA may have more severe symptoms prior to CBT. This is reflected in patients' CORE-OM and HoNOS-ABI scores where FMD patients with a history of physical abuse had a higher pre-treatment mean than FMD patients with no history of abuse[8]. Similar to Glass et al. (2017), we found that patients who did not drop out were more likely to report improvements in their symptoms compared to those who did drop out. Those who do not see immediate improvements in symptoms may become disenchanted, and as a result disengage. Dropping out early also lessens the chance that a patient will have the opportunity to improve. Again, interpretation is limited as these socio-demographic differences were only found in our univariate analysis, but were not significantly different when combined in a logistic regression model. Future studies should assess the effect of severity of symptom and quality of life on adherence to CBT.

While the treatment dropout is likely to be partially explained by patients unwilling to accept a psychological account of symptoms, in CFS, a diagnosis potentially as problematic to patients as an FMD diagnosis, dropout from the CBT arm of the 'Pacing, graded Activity, and Cognitive behaviour therapy, a randomised Evaluation' (PACE) trial was only 11% (White et al., 2011). This rate is significantly lower than that seen in our study but a patient deciding to drop out of an RCT is not entirely comparable to our observational results. Deciding to remain in treatment offered as part of an RCT is likely a qualitatively different decision. It might be fuelled by a wish to contribute to scientific knowledge rather than factors associated with the treatment itself. In addition, RCT studies may make an extra effort and have greater expertise in employing methods to reduce dropout and have more access to financial and administrative resources to avoid dropout compared to well-established NHS clinics.

6.4.2 Strengths and limitations

Our study is the first to assess the outcomes of FMD patients receiving CBT from an outpatient neuropsychiatry clinic. This is a relatively large retrospective study, which like Chapter Five, benefits from the richness of clinical information available in one large, anonymous medical database. The comprehensive search strategy we employed, whereby the records of every patient linked to the service's CBT clinicians was screened for inclusion, means our FMD sample is a good representation of patients seen in the clinic. The relatively large sample size and the inclusion of a control group allow for the detailed exploration of associations in socio-demographic variables, and relatively robust statistical comparisons.

[8] Data unavailable for CSA as the rate of CSA affected less than five patients

We originally hoped to include a larger control group, matching at least two control patients to every FMD patient. The 76 control group patients we included were however the only available candidates who fitted our inclusion criteria. A possible third control group including patients with only NES might serve as a useful comparator in a future study.

One limitation of this study relates to its observational design. While an RCT can make robust conclusions about the effectiveness and efficacy of a treatment, our control group differed only by diagnosis but all patients received the same treatment. We can conclude that CBT appears to have a beneficial effect for a proportion of both patient groups but we do not know whether this improvement is explained simply by a regression to the mean phenomenon or whether the effects observed would be lesser or greater had a waiting group or placebo treatment been used. Our results might serve as a useful pilot study for a larger RCT in this area.

The retrospective nature of this study also has limitations. Like in Chapter Five, any clerical errors made in the CRIS database will be reproduced. Patients were not interviewed face-to-face by the researcher. As such, the experience of receiving CBT cannot be gauged. The author of this study did spend time observing CBT staff meetings and assessment and treatment sessions with FMD patients and this provided valuable insight into the running of the CBT clinic and was a useful aid when reading clinicians' medical notes in CRIS.

The retrospective nature of the study and the use of a medical database meant that type of measures we could use was restricted. This meant potentially useful measures like the Social Functioning Questionnaire or the Illness Perception Questionnaire were not included. A second issue relates to our measures of psychological functioning which may have limited generalisability. We used lifetime prevalence measures to assess anxiety, low mood and fatigue. One might expect to find 100% prevalence for any individual on these measures, regardless of their mental or physical health status. That we did not may reflect the differences in the type and style of medical notes kept by different clinicians. Thirdly, the retrospective study design means we have had to rely heavily on categorical data which have less nuance than continuous outcomes and limits the number of tests we can utilise. The design also precludes us from concluding which elements of CBT sessions were most useful and which techniques brought the most improvement. Such research is difficult however and would likely require the recording of sessions through an observer or the use of video, methods which in themselves might introduce an observer bias.

A further issue relates to patients' clinical outcome scores. The HoNOS-ABI and HoNOS are clinician-rated measures. There is the possibility that clinicians may, consciously or unconsciously, give more favourable scores at the end of treatment. While it can and should be assumed that most staff members are unbiased in their scoring, services often implement quality control measures such as independent assessments to help reduce any potential inflation of results. In our study, we also included CORE-OM and PHQ-9 measures which are self-report scales. We found similar scores across measures and no socio-demographic differences between patients with complete scores and those without. We also conducted an analysis, not reported here, assessing pre- and post-CBT scores according to the treating clinician, and found no differences.

Perhaps a greater concern is the low number of participants who had complete scores at both pre- and post-treatment. It is possible that clinicians do not upload scores to the electronic records if scores are poor or show deterioration with time. We compared the socio-demographic differences of patients with complete scores and those with only one or no available results and found no significant differences between patient groups. The low number of available scores may reflect different clinicians' preferences in using different measures or differences in habits of uploading outcome measures to the patient record system. However, it is unlikely that any such preferences alone will systematically bias our findings.

Our study did not include a follow-up period, so the longer-term prognosis of patients cannot be assessed. A future, prospective study would be helpful in ascertaining whether improvements were sustained over time, the nature of patients' care pathway after their discharge from the CBT clinic, and their long-term clinical, occupational and psycho-social outcomes. In addition, we were unable to investigate prognosis regarding specific functional motor symptomatology due to the heterogeneity of symptom types and our sample size. Nonetheless, this would be a useful addition to a large study in the future.

While our study shows preliminary evidence for the effectiveness of CBT in improving FMD patients' functioning, this research area would benefit from a large RCT with blinded investigators and a wide range of assessment measures. The CODES trial, a large RCT assessing CBT versus standardised medical care will provide robust evidence on the effectiveness of CBT in patients with NES (Robinson et al., 2017), the area of FMD remains under-served in evidence regarding effective treatments.

6.4.3 Conclusions

A proportion of FMD patients respond positively to CBT and the treatment has a moderate dropout rate. While the patients who are offered and go on to accept treatment are a select sample, their clinical scores show good improvements in psychological and physical functioning. These patients present with a range of functional motor symptoms, and many experience pain and weakness.

Many participants accepted a psychological account of symptoms before treatment, but a proportion did not but went on to change their mind and had accepted a psychological account by the end of treatment. Acceptance of the role of psychological factors is helpful in predicting improvement but for a small group of patients, symptoms improve regardless of their belief in the cause.

While our study suggests CBT is effective, we cannot conclude that CBT is a superior treatment to any other intervention and we do not know which specific components of the therapy are most effective. These are topics which would be best addressed in a future large RCT, evidence that is distinctly lacking from existing literature.

Chapter Seven: General discussion and conclusions

In this thesis, I have investigated FNDs as they present to stroke and psychiatric services. The first half of the thesis investigated presentations of patients with unexplained symptoms to stroke settings focusing, in particular, on recently established HASUs. The last two chapters explored presentations of FMD in a large mental health setting, investigating socio-demographic, health and clinical factors as well as the effectiveness of CBT.

Five main findings emerged from these studies:

Functional patients consistently present to stroke settings, constituting 1.7% (95% CI: 1.3% - 2.2%) of all presentations, and 11.8% (95% CI: 9.3% - 14.9%) of stroke mimic presentations. In acute stroke units, patients with functional disorders account for 13.8% (95% CI: 7.9% - 23.2%) of stroke mimic presentations.

Hyper acute stroke clinicians describe an array of potential causes of functional stroke presentations, with some arguing that patients are consciously performing symptoms. Many feel unsure how to discuss potential causes with these patients and 90% of survey respondents do not believe there are clear guidelines on how to manage them.

Patients with unexplained stroke-like symptoms have strongly negative emotional responses to admission to hyper acute stroke wards and feel that they have little control over their symptoms. Two months later, patients are often uncertain about the cause of their admission. 40% continued to experience residual physical symptoms; many experienced anxiety, and often expressed a desire for a more detailed explanation about the potential cause of their symptoms.

Our case-control study examined presentations of FMD to SLaM, a large mental health trust. Our study supports previous epidemiological research showing FMD more commonly affects women, that patients frequently work in social or health care, and frequently have a comorbid physical and functional illness with headache and NES most frequently accounting for these respectively. We found no association between rates of childhood sexual or physical abuse in the FMD group compared to the psychiatric patients in our comparison group, but tentative evidence suggests FMD patients more commonly experience precipitant events that we defined as ‘disruptions to interpersonal relationships’.

Finally, our case-control CBT study indicates that both FMD and patients with organic disease respond to outpatient CBT. Half of the FMD group saw improvements in their physical symptoms, and measures of psychological distress and depression, when available, showed significant clinical improvement between first and last treatment sessions. Of the FMD patients

who were offered CBT but who did not go on to receive therapy, 57% were patients who themselves had refused treatment, for a variety of reasons, higher than the 39% of patients in the control group who themselves refused treatment. This suggests that pre-treatment acceptability for CBT amongst FMD patients is relatively low. Dropout rates after treatment commencement showed no significant difference between FMD and control patients.

The findings and limitations of individual studies have been explored previously. This chapter discusses general issues, including differences in patient groups between studies, differences within FMD symptoms themselves, the gender ratio of FND, the use of medical databases, and potential future service and treatment provisions.

7.1 Between- and within-group difference

A question arising in the introduction of this thesis is whether functional patients who appear in HASUs differ from the FMD patients seen in psychiatric settings. They appear to have certain similarities but differ with regards to symptom chronicity and severity. Functional stroke patients share a similar age and gender profile to the patients we observed in SLaM, and like SLaM patients and the functional patients observed in our meta-analysis, functional stroke patients most commonly experienced weakness. One would expect FMD patients in psychiatric services to have a higher number of comorbid psychiatric symptoms, but a proportion of functional stroke patients also had a history of depression and many described experiencing low mood and anxiety as a response to the admission.

Perhaps the most obvious difference between functional patients in the HASU and FMD patients seen in SLaM was the temporality of their symptoms. 44% of functional stroke patients had transitory physical symptoms which resolved two months after their discharge. While functional stroke patients' physical symptoms were acute, for a proportion of patients, their psychological symptoms of lower mood and anxiety continued two months after discharge.

A proportion of our functional stroke patients likely represent the early stages of a chronic FND course, while patients in our SLaM studies will more often represent advanced stages. On average, SLaM patients experienced symptoms for ten years prior to receiving a functional diagnosis from the Trust. It is possible that if functional stroke patients' psychological symptoms don't resolve quickly, or if they do not receive an adequate referral or early intervention, their symptoms may continue and worsen.

Research suggests only a proportion of functional stroke mimic patients receive a psychological referral. 37.5% of functional patients admitted to a HASU were later referred by their GP to psychological treatments, counselling, pain clinics or mental health services (Gargalas et al., 2015). The remaining patients may not need such a referral, but without longer-term follow-ups this is difficult to conclude. It is well established that a confident diagnosis and early intervention in FND is important as patients have a better prognosis if they have had a shorter duration of symptoms prior to treatment (Aybek et al., 2013; Factor et al., 1995; Jankovic et al., 2006; Lempert et al., 1990; Thomas et al., 2006).

For some patients, a stroke admission will represent a small proportion of a larger, more extensive care pathway, particularly if they are dissatisfied with their original consultation (Crimlisk et al., 1998). Each admission or medical referral increases the risk of harm to the patient from unnecessary intervention. Admission to a stroke ward increases the probability of receipt of thrombolytic therapy. While thrombolysis in non-stroke patients has been found to be relatively safe (Chernyshev et al., 2010; Kostulas et al., 2017; Scott & Silbergleit, 2003; Winkler et al., 2009), it is unclear what the effect of repeated administrations in the same non-stroke patient may be. A case study reported that a patient with a factitious disorder diagnosis received thrombolytic therapy twice and went on to develop a minor groin haematoma (Belagaje et al., 2012).

Acute stroke services require systematic methods of training stroke clinicians in how to explain functional symptoms as well as guidelines and referral methods to prevent symptoms becoming intractable. The two-month follow-up and qualitative methodology in Chapter Four's stroke study cannot fully account for the potential relapse and remission of functional symptoms but prospective, longitudinal research would help identify the long term pathway of functional stroke patients, whether this course differs substantially to patients in psychiatric, medical or neurology outpatients settings, and the protective factors that help some functional stroke symptoms resolve without the need for further referral.

Linked to the issue of whether functional stroke patients differ to FMD patients in psychiatric services is the question of whether different functional disorders are themselves a unified, coherent disorder or whether they should be regarded separately. In the 19th century, French neurologist J-M Charcot attempted to develop a reliable classification of hysterical symptoms but recent debate contests whether functional symptoms represent distinct categorical entities or form one dimension.

Kirmayer and Robbins (1991) proposed a dimensional model that conceived all somatoform disorders as amplifications of normally fluctuating levels of body preoccupation and

awareness. Wessely et al. (1999) argue that drawing distinctions between somatoform syndromes is redundant given the many commonalities between disorders. They allude to the predominance of females, strong associations with psychological distress, high prevalence of childhood trauma and abuse, and difficult doctor-patient interactions as examples of the shared features of somatoform syndromes. They advocate a unidimensional approach arguing that current classifications of somatoform disorders are artefacts of professional medical specialisation and organisation, rather than distinct syndromes (Wessely & White, 2004).

Evidence employing latent variable analysis suggests that there may be a uni-dimensional somatoform syndrome predisposing patients towards developing unexplained physical symptoms, but there is also consistent evidence for coherent and distinct syndromes. Robbins et al. (1997) found evidence to support the conceptualisation of CFS, IBS and fibromyalgia as distinct syndromes while noting a strong overlap between syndromes. Deary et al. (1999) identified five distinct symptom factors, CFS, IBS, fibromyalgia, somatic depression, and somatic anxiety. Fink et al. (2007) found evidence for three specific syndromes: cardiopulmonary, musculoskeletal and gastrointestinal symptoms, arguing that these symptoms represent an underlying phenomenon they term, 'bodily distress'.

With regards to differences within FND itself, previous research highlights differences between NES and FMD patients. NES patients are often younger, more likely to have experienced CSA or a precipitating stressor (Driver-Dunckley et al., 2011; Ekanayake et al., 2017; Stone et al., 2004b). The evidence on psychiatric comorbidity is mixed. Ekanayake et al. (2017) reported that NES patients have higher rates of depression and anxiety than FMD patients. Hopp et al. (2012) however found similar rates in both groups, arguing that NES and FMD represent one coherent disorder, an argument echoed by Erro et al. (2016) who suggested that NES and FMD have a shared psychopathology with distinct phenotypic manifestations. Many of these studies' are derived from data from patients recruited from different clinics however, so referral processes may plausibly account for these differences.

The studies outlined in Chapters Five and Six of this thesis specifically exclude patients with only NES so we cannot draw conclusions on differences between FMD and NES patients. It is possible however to discuss the potential differences and similarities within FMD and to ask whether differing motor symptoms represent distinct entities or a coherent disorder. For example, there is some evidence that patients with weakness and paralysis, have a better prognosis compared to patients with movement disorders like tremor (Gelauff et al., 2014).

In our case-control studies, we observed a wide variation in FMD patients' motor symptoms. A substantial proportion of patients in Chapter Five had symptoms which we classified as 'other',

representing a rich array of motor deficits and abnormalities. In our SLaM studies, most patients had more than one functional motor symptom with 83.7% of patients in Chapter Six with at least two functional motor symptoms, and over 30% in Chapter Five with a comorbid functional disorder. This may also underestimate functional disorder comorbidity as we classified headache as a physical illness.

While reading the medical notes, it was frequently difficult to ascertain which functional symptom was the 'primary symptom'. We abandoned an initial attempt to hierarchically categorise motor symptoms. In addition, our categories are, inevitably, relatively artificial as weakness in one patient may look and feel different in another and was often accompanied by a differing array of comorbid physical and mental health symptoms. It was rare to observe the same collection of symptoms in more than one patient. Finally, the motor symptoms we observed appeared to evolve over time, with some remitting entirely and new ones emerging.

As with many other mental health disorders, FMD's phenotype does not appear to follow a fixed course. Instead, these symptoms seem to represent complex and varied symptomatology, one that is difficult to predict. The complex evolution of symptoms is not peculiar to our study. In one study, patients with NES were followed up between 6 and 12 months after a diagnosis and, in this period, new unexplained symptoms emerged in 23.5% (McKenzie et al., 2011). In a study of FMD patients, 35% went on to develop additional unexplained symptoms (Feinstein et al., 2001).

Reliable classification of disease and disorders is important in the establishment of robust epidemiological data and subsequent effective treatment. While a unified, dimensional approach might help resolve some issues related to the reliability of motor symptoms and their comorbidity with other functional symptoms and disorders, an entirely unidimensional model would obscure the existing, hard-won nuance in this field. Such calls are premature based on current evidence. Many psychological disorders share similar or identical causal pathways and phenotypic commonalities, but nonetheless remain distinct conceptual entities. More importantly, abandoning the current symptom-driven classification system would affect the kind of treatment on offer. An example of this is physiotherapy, a recommended treatment for FMD, but where it would make little intuitive sense to offer this to NES patients.

More generally, unifying symptoms and syndromes under one category does not help address why some patients present with certain functional syndromes or, more specifically why one FMD patient might have a gait disturbance and another experiences tremor or weakness, especially in cases where there is no precipitating physical factor or where disease modelling in friends and family cannot help account for symptom occurrence. While theoretical advances

have been made in understanding the causes of somatoform disorder generally, the field lacks coherent syndrome- and symptom-specific theoretical explanations. Some would argue that a relatively trivial 'trigger', such as a physical injury, often lies behind symptom manifestations (Pareés et al., 2014).

The retrospective nature of our studies meant we could not conduct a longitudinal factor analysis which would have allowed us to identify symptom patterns and their long-term course. FMD would benefit from a large-scale prospective case-control or cohort study which could help assess the development and evolution of FMD symptoms, their course, and the factors predicting their severity and remission.

This thesis was not designed to test a specific theoretical model or to identify specific psychological mechanisms in the development and maintenance of FMD. The aim of this research was to build an evidence base on FND patients' presentations to stroke settings and to utilise and explore existing evidence from a large retrospective database.

Nonetheless, some current psychological accounts of FND may help shed some light on our results. Firstly, theories of attentional processes may be relevant. When distracted for instance, FND patients are frequently less symptomatic. This suggests that patients' attention towards their own movement production and their higher likelihood of monitoring internal sensations may disrupt normal movement. This may be apposite for techniques stroke clinicians could utilise when diagnosing and treating functional patients on the ward.

Research also suggests that FND patients may have an altered style of belief formation, for instance a study found patients demonstrated a 'jumping to conclusions' style of decision making (Parees et al., 2012). This may be relevant to our findings on patients' illness beliefs on the stroke ward where we found functional patients believed their symptoms would have serious consequences on their lives.

Theoretical accounts of FND suggest that patients' beliefs and expectations about bodily functioning are integrated within existing bodily sensory information to produce distorted perceptual experiences (Brown, 2004; Edwards et al. 2012). Such distorted beliefs and expectations could arise through multiple mechanisms but our findings suggest such beliefs may be linked to existing comorbid physical health conditions or difficulties arising from interpersonal problems. The causal relationship between such experiential factors and resulting beliefs is not well understood.

The psychological mechanisms involved in FMD share overlapping characteristics with other unexplained syndromes such as chronic fatigue syndrome and unexplained pain. In Chapters

Five and Six for example, fatigue and pain were common comorbidities amongst FMD patients. Elements of the symptomatology of FMD are not unlike that seen in CFS where the inability to move certain limbs can resemble the extreme fatigue observed in CFS. In FMD, these symptoms are more commonly localised to specific regions of the body and may be less extreme than that seen in CFS, although in Chapter Five's study, there were a small number of FMD patients with complete bodily paralysis.

The psychological models underlying treatments for CFS and FMD share similarities but differ in important ways. CBT models for CFS specifically propose that the symptoms and resulting disability are perpetuated by a fear of symptoms which leads to activity avoidance which perpetuates symptoms. This fear avoidance model differs from the CBT model of FMD which tends to focus more heavily on maladaptive attentional processes and distorted illness beliefs. The specific distraction techniques developed by neurologists in the diagnosis and treatment of FMD for instance are unlikely to be relevant or useful for CFS or chronic pain patients.

The treatment models for FND and unexplained syndromes like CFS do have much in common. Both models address illness beliefs, symptom focus or attention, psychological distress and the perpetuating factors relevant to the patient; however the emphasis on these factors will differ between patient groups and will be affected by the patient's individual formulation. Evident throughout the field of unexplained symptoms more generally however is a dearth of large randomised controlled trials testing the individual components of these models and their longer-term benefits.

7.2 Gender

FND is consistently found to affect more women than men. Established theories exist to help explain the gender differences observed in diseases and disorders like multiple sclerosis (Harbo et al., 2013), autoimmune diseases (Ngo et al., 2014), depression (Ustün, 2000), and heart disease (Maas & Appelman, 2010), but despite its long history, FND lacks a coherent account of its gender disparity.

Cultural theorists attempted to explain the prominence of hysteria amongst women in the 19th century as an exercise in the social control by doctors over an emerging class of working French women (Appignanesi, 2008). While elements of this theory may be true, it misrepresents current evidence by stating that the disorder has all but disappeared. We observed similar rates of females in our meta-analysis study, our HASU qualitative study and in our case-control studies in psychiatric settings. FND exists and continues to affect more women than men, regardless of symptom type or the setting to which patients present.

Why are women more commonly affected than men? Biological processes may play a role. Women with higher anxiety report increased cognitive symptoms like misinterpretations and catastrophizing thoughts in the premenstrual phase compared to the follicular phase (Nillni et al., 2012). Laboratory studies found women were more sensitive to external environmental cues when noticing and defining physical symptoms (Kirmayer & Robbins, 1991). Genetic factors may contribute although there is little current evidence for FND specifically. Our crude assessment of a family mental health history in Chapter Five for example found half of FMD patients had a family member with a mental health problem and, most commonly, this relative was a mother. Environmental exposure could also explain this finding or interact with genetic processes.

Psycho-social factors have been attributed to the development of FND in women. These include social factors such as greater social and cultural permission for women to express psychological and physical distress as well as the specific social roles and responsibilities that women assume in society (Kirmayer & Robbins, 1991). This was explored in Chapter Five's case-control study. Female FMD patients were more likely to work in social or health care settings, suggesting they occupy a specific economic position - one characterised by low pay, high responsibility and dependent interpersonal relationships. Our logistic regression results in Section 5.3.6, suggest that when gender and marital status are accounted for however, neither health or social care work, nor being a carer in themselves are predictive of an FMD diagnosis. It is possible that the high proportion of female health and social care workers is an artefact of the fact that 95% of all social care workers are women and that carers are more likely to have a lower SES (Eborall, 2005).

Ways in which the body is conceptualised and symptoms are experienced may differ between the genders, contributing to an increased risk of developing unexplained symptoms. Social psychological research suggests women and men hold different conceptualisations of the body with women often associating the word 'body' in its desiccated, anatomical parts and men conceptualising it as a functional whole (Jodelet, 1993). Embodied cognition research may shed light on this subject with findings suggesting that sensorimotor experience evoke psychological responses, for example nodding your head up and down can affect people's level of agreement with an argument (Wells & Petty, 1980). This may operate differently in men and women, for example, making a fist can lead men to increase feelings of power, while for women, it can lead to a heightened sense of powerlessness (Schubert, 2004). While psychological interventions for FND are premised on the assumption that reducing dysfunctional cognitions can help resolve unexplained physical symptoms, embodied cognition

research suggest that treatments that directly involve the body might directly affect those psychological processes through bottom-up processes.

Women's higher risk of exposure to childhood trauma such as physical and sexual abuse has been proposed as a potential explanation for FND's gender ratio (Keynejad et al.). Chapter Five's case-control study however, found that while rates of childhood sexual and physical abuse and abuse occurring in adulthood were higher in female FMD compared to male FMD patients, rates did not differ between female cases and controls. In our study, this specific type of trauma is therefore equally common in women in both groups and while exposure to CSA may play a role in the development of FMD, it does not appear to be a specific risk and may be a risk for all mental disorder in general. It is possible that experiences of abuse interact with negative illness beliefs, social deprivation, personality characteristics, depression and anxiety, and mediate or moderate the relationship between trauma and FMD, but it is likely that such a pathway exists in the development of many psychological disorders.

Kuehner (2017) argues that structural gender inequality at the state level, as measured by political participation, economic autonomy, and access to reproductive rights affects depression rates in women and it is reasonable to assume similar processes may affect the occurrence of FMD in women. It is plausible that individual differences as well as meso-level processes such as group membership, neighbourhood effects, family dynamics, social networks, and larger macro-level social structures like legal frameworks, health care structures, and culturally sanctioned beliefs about neurological all interact in the development of FMD in women. There has been little research which combines micro-, meso- and macro-level processes, but longitudinal cross-cultural research that incorporates methods of psychological enquiry may help unravel some of these broader, structural processes and shed light on the processes that lead to the manifestation of FND.

7.3 Data collection and the use of medical records

> *"If one looks at the charts of patients institutionalised in asylums and state hospitals in the 1920s and 1930s, one finds extremely detailed clinical and phenomenological observations, often embedded in narratives of an almost novelistic richness and density…this richness and detail and phenomenological openness have disappeared, and one finds instead meagre notes that give no real picture of the patient or his world…and are of little use in helping us bring about the synthesis of neuroscience with psychiatric knowledge that we so need"*
>
> Oliver Sacks (1995) Scotoma: neglect and forgetting in science

Medical records account for clinicians' observations, interactions with patients and the interventions they employ. Within institutions they can serve as a means of communication between staff members involved in an individual's care. They are also a legal document that justifies adequate care. With the transformation of clinical notes into large electronic medical databases, these notes have begun to form part of case registers which are being harnessed to assess treatment interventions and outcomes.

Our case-control studies were necessarily influenced and restricted by the format of our case register. The most significant advantage of using CRIS in our studies was its size, particularly for FMD, a disorder with a relatively low prevalence, where community studies are impractical. Using CRIS in our Chapter Six allowed us to observe CBT in its naturalistic setting, and its findings have the potential to be more generalisable than standard RCTs.

The disadvantage is that inaccuracies in the case register will be reproduced in our research. Keeping records up to date can be problematic for clinicians and where contradictions appear in the notes, it can be difficult to assess what information is correct. There is no way for a researcher to know exactly how accurate the information provided is. The retrospective nature of this research limits our ability to draw causal inferences; a disadvantage inherent in most observational research.

One of the potential problems in using an electronic database like CRIS, and the problem outlined by Oliver Sacks, is that the use of case registers can lead to an emphasis on standardised, categorical checklists and short templates rather than richer, 'novelistic' clinical notes that account for and describe patients' phenomenological experiences.

The data collection method used in Chapters Five and Six of this thesis departs from many previous CRIS studies. Our approach was an attempt to utilise the qualitative richness and detail of the clinical notes. A number of issues arose however as a result. Firstly, it was time consuming. Had we relied on structured output alone, data could have been exported without the need to read the notes. Instead, our method took the author over a year. Secondly, as the database is updated every night, there was an urge to want to continue collecting new cases to increase our sample size. A relatively arbitrary decision had to be made to stop data collection in order to progress the study. This decision was not based on a pre-defined power calculation but rather on the time available to the researcher.

Relying on structured data alone however would limit the type and range of information we could collect. This tension between the need for larger sample sizes as well as rich detail is common in much epidemiological research and our approach attempted to marry the two.

The second issue relates to styles in clinicians' note writing. There was tendency for clinicians to rely on documentation shortcuts like abbreviations, deliberately vague language or generic terminology. In some cases clinicians spent a large portion of their notes describing attempts to contact patients or any risk management issues. This style often meant there was more information on secondary issues related to clinical care rather than the actual clinical interactions or the patients' experiences.

We were helped by the fact that many of the clinical notes are written in the traditional 'Maudsley' assessment style which includes a family, developmental and social history, a Mental State examination, a physical examination, and the clinician's formulation and diagnosis (Owen et al., 2014). The consistent structure of these notes and their depth of detail allowed for the collection of rich information on early life events and recent precipitants. Our post-hoc categorisation of such information meant the categorisations were informed by the data itself and not by any pre-conceived bias. The tradition of note-taking by SLaM psychiatrists suggests that Sack's (1995) pessimism regarding the shortcomings of modern medical notes may not be universal.

A more extreme extension of Sack's argument is that with technological medical advances, like the development of large electronic databases and the standardisation of assessments, clinicians can neglect their role as listeners to the stories, thoughts, and feelings of their patients (Reiser, 1978). The studies in Chapter Four and Five help address some of this shortage in attempts to understand phenomenological and experiential accounts of functional symptoms, but the advances in stroke care coupled with the seeming lack of intervention or attention to functional stroke patients suggests that such a worry is not entirely unwarranted. As case registers become more technologically advanced with the inclusion of biological and imaging data, there is an even greater need to find ways and space to account for and include first person experiences.

7.4 Future research

The following sections discuss potential future improvements in services and treatments.

7.4.1 Services

The distinct dichotomy in neurological and psychiatric services perpetuates the dualism inherent within conceptualisations of functional neurological symptoms and it may hinder the treatment of functional symptoms, with patients moving between such services without coherent treatment or any continuity of care. This may be system may be maintained as clinics and hospitals are often reimbursed for conducting diagnostic tests and treatments, but tend

not to be rewarded for good communication or effective referral (Creed et al., 2011). In some ways, the structure of this thesis itself mirrors the institutional divide in neurology and psychiatry, serving to illustrate its pervasiveness.

Our findings in Chapter Three and Four suggest that patients in stroke settings are often denied adequate explanations about their symptoms and possible treatments. This is likely fuelled by neurologists and physicians feeling ill-equipped to provide what they view as psychological or psychosocial explanations. Of those functional stroke patients that do receive a referral to psychological services, results from Chapter Six suggest, a proportion will refuse to accept a referral which they may view as stigmatising or unnecessary.

To manage functional symptoms effectively, a combined psychological and neurological approach is needed (Mula, 2013). The integration of these services could help reduce stigma and self-stigma amongst patients concerned they will be labelled with a psychological disorder or who fear being accused that their symptoms are 'made up'. It could also encourage neurology staff to deal with the psychological aspects of neurological disorders, which are currently described as under-recognised and under-treated (White et al., 2012). A number of structural service changes might help lessen the dichotomy between neurological and psychological treatments and move towards an integration of disciplines.

Firstly, the assimilation of training of neurology and psychiatry trainees might help forge links between the disciplines. However, given the continued trend towards ever greater specialisation in medical training, and the length of neurology training programmes in particular, a merging of psychiatric and neurological training is unlikely.

Consultation-liaison psychiatry services are one of the few psychiatric subspecialties which assess and treat FND patients in medical settings, often working at the intersection of medicine and psychiatry. Their presence in hospitals is important but FND patients may be relatively underserved by this speciality as pressures on services grow. To avoid encumbering services, hospital physicians may choose to refer FND patients to GPs or discharge them, rather than burdening overstretched services within the hospital.

Neuropsychiatry services may help reduce the divide. The prefix 'neuro' may be advantageous as it likely to be more palatable to FND patients. Neuropsychiatry, in its current status however, needs to extend beyond tertiary provision. Current neuropsychiatric services serve only a small number of regional UK centres and its provision has been described as patchy and inadequate (Agrawal et al., 2008). Clinicians working further away from neuropsychiatry services have a lower awareness of them and do not know how to access them, increasing the possibility of unmet need in rural areas (Fleminger et al., 2006).

Neurologists often manage FND patients within their outpatient clinics but restrictions on their time, may mean appointments are short and that they are unable to offer extensive follow-up appointments. Neurologists' interventions may more commonly take the form of diagnostic explanation or referral to another service, rather than a specific treatment (Stone, 2009). It is possible that this approach is sufficient for a proportion of patients, but on the stroke ward, not all clinicians provide even this rudimentary intervention, and it is unlikely to be sufficient for patients with severe or chronic symptoms or for patients with significant psychopathology.

An alternative approach is to adopt elements of the German system of psychosomatic medicine. This system has three levels. The first involves intensive GP training in psychosomatic medicine. GPs receive a curriculum of 80 hours training, with over 60,000 of the 360,000 German GPs completing additional courses on psychosomatic care. In addition, GPs are financially reimbursed for longer consultations with functional patients and if they feel limited in the kind of treatment they can offer, there are local collaborative groups with psychotherapists which they can join to help develop specific treatments (Creed et al., 2011).

The second level involves outpatient psychotherapy from psychologists and doctors. CBT, albeit provided by private health insurance, can be offered to patients for more than 100 sessions. As in the UK, only a proportion of patients are willing to receive psychological treatment and brief CBT interventions are offered through consultation-liaison psychiatry services in medical departments. It is hoped that engagement in such a service might prompt the psychologically-sceptical patient to engage at a later stage in more intensive therapy if necessary.

The third level of care involves the provision of inpatient and outpatient treatment through psychosomatic hospitals which cover regions as well as departments of psychosomatic medicine within general hospitals (Zipfel et al., 2016). These hospitals are run by both clinical psychologists and internal medicine physicians with psychotherapeutic training (Buhring, 2012). Treatments offered include nonverbal therapies like art, music and motor therapy, physiotherapy, biofeedback techniques and a range of psychotherapies, more diverse but not unlike the Lishman Unit in London (McCormack et al., 2013).

Psychosomatic medicine in Germany has a distinct advantage in that it is not a subspecialty of psychiatry but represents its own discipline. Scheidt (2017) argue that the German system is particularly distinctive in that its cross-disciplinary approach can be integrated into any clinical medical speciality. Such an approach would potentially allow for patients with a range of functional syndromes to be cared for in one setting with interventions that focus on psychopathology rather than the unexplained symptoms themselves, unlike current tertiary

inpatient services in the UK which are symptom specific, for example the Lishman Unit, a neuropsychiatry service, or specialist inpatient chronic fatigue services (McDermott et al., 2014).

In the German system, patients admitted with functional stroke symptoms could be discharged to a psychosomatic ward where they receive integrated medical and psychological care with none of the potential stigma that might come with a psychological referral.

This integration of both physical and psychological techniques and the ability of one service to offer a wide range of techniques in both inpatient and outpatient settings, is likely the true exemplar of the biopsychosocial model.

7.4.2 Treatment

Our study found evidence that CBT is clinically effective in the treatment of FMD, however we are unable to identify why the therapy might be effective or the most efficacious therapeutic components. Most current research on psychological treatments for FMD has tested forms of CBT, with few testing third-wave psychotherapies. While CBT employs methods like grounding and relaxation techniques to help patients engage with their bodily processes, the aim of such tools is the general reduction of panic and anxiety while the body itself tends not to be the primary focus of the therapy.

A possible treatment for FMD that has not been widely considered is that of body psychotherapy. While physiotherapy is specifically recommended in the treatment for FMD, there are no trialled, specific manuals which incorporate psychological interventions with physiotherapeutic techniques. Instead, it is recommended that patients with a psychiatric comorbidity are referred to psychotherapy after they have seen motor symptom improvements in physiotherapy (Nielsen et al., 2014). Body psychotherapy might avoid the need for two separate referrals, as it employs physical and psychological approaches.

Body psychotherapies "*explicitly use body techniques to strengthen the dialogue between patient and psychotherapist about what is being experienced and perceived…the body is considered a means of communication and exploration*" (Heller, 2012). Body psychotherapy directly addresses the inherent link between cognition and somatic experience without making any artificial distinctions between mind and body.

One form is 'body-oriented psychological therapy' which is delivered in a group format. Techniques include 'checking in' where patients are asked how their body feels, 'warming up' using movements like stretching and breathing, 'structured tasks' such as demarcating the body's boundaries with props or mirroring others' movements, and 'creative movements' like

group mirroring or creating group sculptures. Throughout, there is a focus on individual difficulties and problem-solving strategies and discussing experiences with the group, identifying the impact of symptoms on their lives and attempting to identify solutions to individual difficulties (Rohricht & Priebe, 2006).

Body psychotherapy has shown positive results in the treatment of patients with chronic depression (Röhricht et al., 2013) although it was found to have limited effectiveness in improving the negative symptoms of schizophrenia (Priebe et al., 2016). Nevertheless, this study did report significant improvements in movement disorder symptoms, although this was not a primary outcome.

Body psychotherapy relies on 'bottom-up' conceptualisations of psychological symptoms, emphasising the significance of physical and sensory perceptions. This approach specifically relates to current psychological models of FND. Brown (2004) argued that unexplained physical symptoms are moderated by an over-reliance on top-down brain processes like belief rather than 'bottom-up' processes like somatic perception. The theory is supported by evidence that patients with FMD have poor sensitivity to internal body signals (Ricciardi et al., 2016), a weaker ability to identify and describe emotions (Demartini et al., 2014), and those with a high number of medically unexplained symptoms are less responsive to the rubber hand illusion, suggesting a decreased emphasis on bottom-up visual input compared to top-down processes (Miles et al., 2011). Body psychotherapy might be one way to help reduce the strength of these top-down processes, and help patients attenuate to bodily processes while the group dynamics might help improve personality issues (Blum et al., 2008).

7.5 Concluding remarks

FND is a disorder with a rich history. Functional neurological symptoms occur in many medical settings and every doctor will encounter these symptoms at some stage in their career. Stigmatising views about functional symptoms, a lack of understanding about the disorder coupled with increasing financial pressure on health services may serve to entrench these symptoms and worsen patients' experiences in medical settings. Such processes may lead to increased self-stigma amongst patients and reluctance to receive psychological treatment when appropriate. As new diagnostic tools and treatments emerge, it is likely that new forms of functional symptoms will develop and present to new services. These services will need to develop ways to treat FND as current methods of discharging patients, often with vague or inconclusive letters to GPs, may be serving to entrench functional symptoms.

Progress in the understanding and treatment of FND has been hampered by the fragmentation and segmentation of medical and psychological services. The unification of services, or an alliance between disciplines would have distinct advantages for FND patients.

FND is a disorder with a consistent incidence, and with distinct epidemiological characteristics. It is also a disorder with a relatively unstable symptomatology, one that often does not follow a predictable course and is different to that seen in organic neurological disease. Future research which applies a prospective methodology might help understand the reliability and course of the disorder and a greater number of RCTs are required in the area of motor symptoms specifically.

As epidemiological understandings of FND develop rapidly, in part thanks to technological advances like large retrospective case registers and their linkages with other data sources, our theoretical accounts must also advance to help the interpretations of emerging findings. These theoretical approaches need to incorporate emerging phenomenological, biological, psychological and social accounts, to help advance our understanding and develop better treatments in the future.

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Appendices

Appendix 2.1: Checklist for the assessment of quality of quantitative studies

Table 70 Checklist for assessment of quality of quantitative studies from Kmet et al.'s (2004) paper

Criteria		Yes (Score"2")	Partial (Score"1")	No (Score"0")	N/A
1	Question/ objective sufficiently described?				
2	Study design evident and appropriate?				
3	Method of subject/comparison group selection or source of information/input variables described and appropriate?				
4	Subject (and comparison group, if applicable) characteristics sufficiently described?				
5	If interventional and random allocation was possible, was it described?				
6	If interventional and blinding of investigators was possible, was it reported?				
7	If interventional and blinding of subjects was possible, was it reported?				
8	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias? Means of assessment reported?				
9	Sample size appropriate?				
10	Analytic methods described/justified and appropriate?				
11	Some estimate of variance is reported for the main results?				
12	Controlled for confounding?				
13	Results reported in sufficient detail?				
14	Conclusions supported by the results?				

Appendix 2.2: Exclusion criteria applied across all studies

Table 71 List of exclusion criteria applied to study samples and their frequency across studies one to nineteen

Excluded if: / **References (1-19):**	Agarwal	Ali	Artto	Ay	Barker	Berglund	Bray	Broadley	Brunser	Chalela	Chan	Chang	Chen, Bogosavljevic	Chen, Sun	Chenkin	Chernyshev	Cordonnier	Cramer	Cumbler
Patients who died in the medical setting																	•		
Patients who did not undergo MRI, CTA or CT										•									
Patients presenting via telemedicine or by telephone		•																	
Aged under-18														•					
Unable to give informed consent or declined consent							•												
Stroke symptoms of more than 5h duration																		•	
Stroke symptoms of less than 24h duration																			
Stroke suspected after 24h of symptom onset																			
Patients with diagnosis of subarachnoid haemorrhage							•												
Treated after 4.5h of symptom onset																			
Hypodensity of 1/3 or more of the MCA territory													•						
Patients not given rt-PA												•	•			•			
Patient was unconscious, in a coma, stupor, experienced trauma							•						•	•					
Incomplete Data	•	•					•				•								
No exclusion criterion information given																			•
No exclusion criterion applied in paper				•	•				•						•				

Table 72 List of exclusion criteria applied to study samples and their frequency across studies twenty to forty

Excluded if:	Damasceno	Dassan	El Husseini	Ferro	Foerch	Forster	Fothergill	Gargalas	Gioia	Giraldo	Glickman	Guillan	Hand	Harbison	Hemmen	Herzberg	Jiang	Karlinski	Kose	Kothari	Lewandowski
Patients who died in the medical setting																					
Patients who did not undergo MRI, CTA or CT																					
Patients presenting via telemedicine or by telephone																					
Aged under-18		•					•				•						•				
Unable to give informed consent or declined consent																					
Stroke symptoms of more than 5h duration																					
Stroke symptoms of less than 24h duration																					
Stroke suspected after 24h of symptom onset															•						
Patients with diagnosis of subarachnoid haemorrhage									•				•			•					
Treated after 4.5h of symptom onset						•				•											
Hypodensity of 1/3 or more of the MCA territory																					
Patients not given rt-PA						•				•											•
Patient was unconscious, in a coma, stupor, experienced					•											•					
Incomplete Data			•						•							•				•	
No exclusion criterion information given																					
No exclusion criterion applied in paper				•				•						•							
References (20-40):																					

Table 73 List of exclusion criteria in studies forty-one to sixty

Excluded if: / References (41-60):	Leys	Libman	Martínez Fernández	McNeill	McWhirter	Mehta	Merino	Moeller	Montaner	Mouradian	Nor, Davis	Nor, McAllister	Norris	Onwuekwe	Puetz	Quenardelle	Ramanujam	Reid	Rizos	Romano
Patients who died in the medical setting																				
Patients who did not undergo MRI, CTA or CT																				
Patients presenting via telemedicine or by telephone																			•	
Aged under-18											•						•			
Unable to give informed consent or declined consent					•				•											•
Stroke symptoms of more than 5h duration																				
Stroke symptoms of less than 24h duration																				
Stroke suspected after 24h of symptom onset									•											
Patients with diagnosis of subarachnoid haemorrhage				•																•
Treated after 4.5h of symptom onset																				
Hypodensity of 1/3 or more of the MCA territory																				
Patients not given rt-PA						•														
Patient was unconscious, in a coma, stupor, experienced trauma																				
Incomplete Data															•		•			•
No exclusion criterion information given																				
No exclusion criterion applied in paper	•		•				•			•		•	•	•		•		•		

Table 74 List of exclusion criteria applied to studies sixty-one to eighty

Excluded if:	Rostanski	Sarikaya	Scott	Sequeira	Sharma	Shellhaas	Sibon	Simonsen	Sivakumaran	Smith	Spokoyny	Thomassen	Tobin	Tsivgoulis	Vanni	Vatankhah	Vroomen	Weir, Buchan	Weir, Murray	Whiteley
Patients who died in the medical setting																			•	
Patients who did not undergo MRI, CTA or CT																			•	
Patients presenting via telemedicine or by telephone																				
Aged under-18					•						•						•			
Unable to give informed consent or declined consent										•					•					
Stroke symptoms of more than 5h duration																				
Stroke symptoms of less than 24h duration																				•
Stroke suspected after 24h of symptom onset					•					•										
Patients with diagnosis of subarachnoid haemorrhage																				
Treated after 4.5h of symptom onset								•						•						
Hypodensity of 1/3 or more of the MCA territory								•												
Patients not given rt-PA	•	•	•					•	•		•			•						
Patient was unconscious, in a coma, stupor, experienced trauma					•		•								•					
Incomplete Data				•	•						•					•				
No exclusion criterion information given																		•		
No exclusion criterion applied in paper												•	•							
References (61-80)																				

Table 75 List of exclusion criteria applied to studies eighty-one to eighty-seven

Excluded if: / References (81-87)	No exclusion criterion applied in paper	No exclusion criterion information given	Incomplete Data	Patient was unconscious, in a coma, stupor, experienced trauma	Patients not given rt-PA	Hypodensity of 1/3 or more of the MCA territory	Treated after 4.5h of symptom onset	Patients with diagnosis of subarachnoid haemorrhage	Stroke suspected after 24h of symptom onset	Stroke symptoms of less than 24h duration	Stroke symptoms of more than 5h duration	Unable to give informed consent or declined consent	Aged under-18	Patients presenting via telemedicine or by telephone	Patients who did not undergo MRI, CTA or CT	Patients who died in the medical setting
Winkler					•											
Wojner	•															
Wolf	•															
Yaghi					•											
Zanaty	•															
Zinkstof					•											
Zweifler	•															

*The following papers used exclusion criteria that occurred only once across studies: Patients with normal diffusion-weighted MRI but an unclear diagnosis at hospital discharge and patients with clinically probable stroke or TIA but normal MRI were excluded in Sarikaya et al.'s (2012) paper. Patients with an initial clinical exam showing no stroke were excluded from Herzberg et al.'s (2014) paper. Patients with haemoglobin levels less than 12.5 g/dL for women and 13.5 g/dL for men, patients with untreated systolic, blood pressure less than 90 mm Hg, and patients with untreated diastolic blood pressure less than 50 mm Hg were excluded from Sharma et al.'s (2014) paper. Patients with systolic blood pressure above 185 mm Hg or diastolic blood pressure above 110 mm Hg; rapidly improving or minor symptoms were excluded from Bray et al.'s (2005) paper. Shellhaas et al.'s (2006) paper excluded participants aged over 18. Smith et al. (2009) and Broadley et al. (2003) excluded patients who suffered stroke while inpatients. Damasceno et al. (2010) excluded patients who had been living in Maputo, Nigeria for less than 12 months. Patients with intracerebral haemorrhage, pre-existing disability, cancer, comorbidity with pro-inflammatory conditions or clinical signs of infection were excluded from Dassan et al.'s (2012) paper. Patients with ischemic stroke, TIA, ICH within three months of admission or a diagnosis ever of brain tumour were excluded from Foerch et al.'s (2012) paper. Fothergill et al. (2013) excluded patients who were not assessed using the ROSIER scale. Chalela et al. (2007) excluded patients with subdural haematoma and patients with TIA without symptoms or signs. Sivakumaran et al. (2016) excluded all thrombectomy cases. Glickman et al. (2011) excluded patients with overt intracranial haemorrhage on their initial CT scan. Karlinski et al. (2015) conducted their study in a neuropsychiatric hospital so all patients were supposed to suffer from either a neurological or psychiatric condition. Kose et al (2013) excluded patients aged under 65. Libman et al. (1995) excluded non-admitted hospital patients. Artto et al. (2012) excluded patients with a diagnosis of basilar artery occlusion. Moeller et al. (2008) excluded patients aged under 16. Ali et al. (2014) excluded patients with unverified age data and basilar artery occlusion.

Appendix 2.3 Definitions of stroke across papers

Table 76 Definitions of stroke used across papers

Stroke definition	*n*	Studies
Stroke and TIA	20	Bray, Girlado, Nor 2004, Nor 2005, Scott & Silbergleit, Tobin, Jiang, Reid, Vanni, Smith, Ay, Ferro, Fothergill, McNeill, Berglund, Mouradian, Broadley & Thompson, Wolf, Weir & Buchan, Karliński
Stroke	15	Agarwal, Ali, Hand, Kose, Libman, Winkler, Yaghi, Zanaty, Ramanujam, McWhirter, Thomassen, Vatankhah, Wojner, Simonsen, Gargalas
IS, includes AIS	12	Brunser, Mehta, Tsivgoulis, Zinkstof , Dassan, Herzberg, Sarikaya, Guillan, Lewandowski, Glickman, Sivakumaran, Hemmen
IS, TIA and intracranial haemorrhage	5	Puetz, Martínez Fernández, El Husseini, Sharma, Cumbler
IS, TIA, haemorrhagic stroke	3	Chenkin, Cramer, Chen
IS and haemorrhagic stroke	2	Montaner, Vroomen
AIS and neuroimaging negative acute cerebral ischemia	2	Spokoyny, Chernyshev
IS and intracerebral haemorrhage	2	Foerch, Zweifler
IS, TIA and intracerebral haemorrhage	2	Gioia, Rizos
Stroke, TIA & SAH	2	Moeller, Harbison*
Hemispheric and posterior fossa stroke	1	Artto
AIS and aborted IS	1	Chang
Acute MCA territory ischaemia	1	Chen, Bogosavljevic
Stroke/acute cerebrovascular event	1	Förster
Definite, probable or possible AIS and intracranial haemorrhage	1	Merino
IS, CVT, TIA and intracerebral haemorrhage	1	Romano
AIS, TIA, cerebral sinovenous thrombosis and intracranial haemorrhage	1	Shellhaas
Cerebral infarction, cerebral haemorrhage and TIA	1	Norris
Brain infarct, SAH, TIA and intracerebral haemorrhage	1	Kothari
Cerebral infarction & intracranial haemorrhage	1	Weir
Stroke, TIA and carotid stenosis	1	Barker
IS, SAH and intracerebral haemorrhage	1	Onwuekwe
Acute cerebrovascular disease	1	Whiteley
Stroke, TIA, old stroke	1	Damasceno**
SAH, CVT, TIA, constituted vascular accident, cerebral haemorrhage, spinal ischemia, cervical artery dissection without CVA and arteriovenous malformation without CVA	1	Cordonnier
IS, TIA, SAH, CVT, spinal stroke and intracerebral haemorrhage	1	Leys
AIS, TIA, intracerebral haemorrhage	1	Chan
AIS & acute intracranial haemorrhage	1	Chalela
Infarctions, TIAs and haemorrhages	1	Sibon
Stroke, TIA and intracranial haemorrhage	1	Sequeira
IS, TIA, CVT, intracranial haemorrhage, medullar pathology, SAH	1	Quenardelle***
AIS, aborted stroke and TIA	1	Rostanski

*subarachnoid haemorrhage classified as stroke mimic in paper but reclassified as stroke for this review
** Old stroke and TIA counted in stroke group by review author, patients classified as "outside Maputo" not counted in analyses
*** Subarachnoid haemorrhage (*n* =8) is counted as an stroke mimic in this study and was not altered by author to allow the reporting of demographics
Abbreviations: AIS = Acute Ischemic Stroke, CVT = Cerebral Venous Thrombosis, CVA = Cerebrovascular Accident, IS = Ischaemic Stroke, MCA = Middle Cerebral Artery, SAH = Subarachnoid Haemorrhage and TIA= Transient Ischemic Attack

Appendix 2.4: Most common stroke mimic diagnoses across studies

Table 77 The most common stroke mimic diagnoses and the frequency with which they occur across studies

Most frequent differential diagnoses	**Number of papers where SM diagnosis is most frequent**	**Total number of patients, *n***
Seizure	22	190
Conversion Disorder	14	208
Migraine	11	221
Epilepsy	4	89
Sepsis	2	31
Other	2	103
Neuropathy	2	41
Metastatic cancer/tumour	2	44
Encephalopathy	2	46
Vertigo	1	39
VBI attack	1	16
Vasovagal episode	1	3
Toxic metabolic disorder	1	34
Syncope	1	23
Old deficit	1	11
Musculoskeletal abnormalities	1	3
Metabolic infectious	1	58
Infectious cause	1	8
Hypotension	1	11
HIV	1	27
Delirium	1	23
“Nothing negative found”	1	16
“Internal medicine patients”	1	127
“Cardiac”	1	7

Appendix 2.5: Functional disorder synonyms across studies

Table 78 Frequency of functional disorder synonyms across studies

Functional term	n	Papers
Conversion Disorder	19	Ali, Artto, Brunser, Chang, Förster, Hemmen, Libman, Mehta, Scott & Silbergleit, Tsivgoulis, Vroomen, Winkler, Chernyshev, Sarikaya, Lewandowski, Ferro, Zweifler, Cumbler*, Broadley
Functional	10	Tobin, Reid, Ay, McWhirter, Whiteley, McNeill, Simonsen, Cumbler*, Gargalas, Sivakumaran
Psychiatric	7	Harbison, Kose, Rizos, Sharma, Cordonnier, Cumbler*, Wolf
Somatisation	5	Nor (2005), Spokoyny, Dassan, Jiang, Fothergill
Psychogenic	4	Shellhaas, Zinkstof, Chenkin, Moeller*
Somatoform Disorder	3	Chen(2011)*, Giraldo, Guillan
Medically unexplained	2	Moeller*, Cumbler*
Functional/psychological	2	Nor (2004), Weir
Psychological	2	Sequeira, Quenardelle
Left hemiparesis due to anxiety	1	Chen (2011)*
Right hemiparesis due to anxiety	1	Chen (2011)*
Functional/medically unexplained	1	Hand
Conversion reaction	1	Yaghi
Functional brachiofacial hemiparesis	1	Herzberg
Psychoneurosis	1	Norris
Anxiety attack	1	Ferro*
Depression	1	Ferro*
Non-organic hemiparesis	1	Leys
*Studies using more than one functional disorder category/definition		

Appendix 2.6: Studies reporting no FND patients in their stroke mimic breakdown

Table 79 Studies reporting zero functional disorder patients as stroke mimics

	Bray et al. 2005	Kothari et al. 1995	Foerch et al. 2012
Sample n (%)	100	86	205
Stroke patient n (%)	73 (73)	62 (72)	202 (98.5)
Stroke mimic n (%)	27 (27)	24 (27.9)	3 (1.4)
Study setting	Emergency medical service	Ambulance	Stroke unit
Study design and aim	Prospective validation of prehospital screening tools	Retrospective record review	Prospective study of suspected acute stroke
Assessment type	Paramedics were instructed to complete a MASS assessment on all designated EMS dispatches for 'stroke' that were symptomatic and conscious	Final discharge diagnosis and ultimate disposition were abstracted from the inpatient chart.	Final diagnosis established at hospital discharge on the basis of all clinical data, brain imaging, lab testing and other examinations
Stroke mimic diagnoses	7 cardiac, 5 seizure, 3 hypoglycaemia, 3 subdural hematoma, 3 fracture, 2 tumour, 1 sepsis, 1 migraine, 1 vertigo, 1 Parkinson's disease)	8 Infection/sepsis, 5 syncope, 2 cardiac disease, 2 seizure, 1 brain metastasis, 2, drug overdose, 1, hyponatremia, 1 arthritis, 1 global amnestic syndrome, 1 radial nerve palsy	1 migraine with aura, 1 endocarditis with septic encephalopathy, and 1 focal epilepsy

Appendix 2.7: Age and gender of medical mimic and functional mimic patients from studies reporting demographic details

Table 80 Age and gender profile of medical mimic and functional disorder patients from individual papers reporting demographic details

Study	Study setting	SM n	MM n (%)	FD n (%)	MM mean age (SD)	FD mean age (SD)	MM females n (%)	FD females n (%)
Artto	Stroke centre	14	10 (71.4)	4 (28.6)	53.1 (12.6)	56.5 (2.3)	7 (70)	4 (100)
Ay	Stroke centre	10	9 (90)	1 (10)	72 (14)	49	4 (44.4)	1 (100)
Chen 2011	Stroke centre	7	2 (28.6)	5 (71.4)	80.5 (7.8)	42.6 (9.4)	1 (50)	2 (40)
Ferro	Primary care & ED	21	15 (71.4)	6 (28.6)	68 (17.4)	60.3 (12.1)	4 (26.7)	6 (100)
Gargalas	Acute stroke	261	163 (62.5)	98 (37.5)	63.5 (16.7)	49.1 (18.8)	81 (49.7)	62 (63.3)
Guillan	Stroke centre	15	10 (66.7)	5 (33.3)	53.1 (15.1)	47.6 (7.7)	6 (60)	4 (80)
Sarikaya	University hospital	23	20 (87)	3 (13)	62.8 (20.3)	59 (15.4)	8 (40)	2 (66.7)
Scott	Teaching hospital ED	6	2 (33.3)	4 (66.7)	63.5 (33.2)	38.5 (11.1)	-	-
Vroomen	Stroke centre	32	19 (59.4)	13 (40.6)	46.3	43	12 (92.3)	10 (76.9)
Winkler	Teaching hospital stroke centre	7	6 (85.7)	1 (14.3)	70.6 (14)	53	3 (50)	0 (0)
Wolf	ED	263	226 (86)	37 (14)	65.6	62 (19)	117 (51.8)	23 (62.2)
Total *n*		659	482 (73.1)	177 (26.9)	63.8 (4.7)[a]	51.6 (6.5)[a]	243 (50.6)[b]	114 (65.9)[b]

FD = Functional disorder; MM = Medical mimic; SM = Stroke mimic

[a] Statistically significantly difference in age (t = 22.8, df = 246, p = 0.001)

[b] Statistically significant difference in rate of females (χ^2 =12, df = 1, p = 0.005)

Appendix 2.8: Stroke mimic forest plot

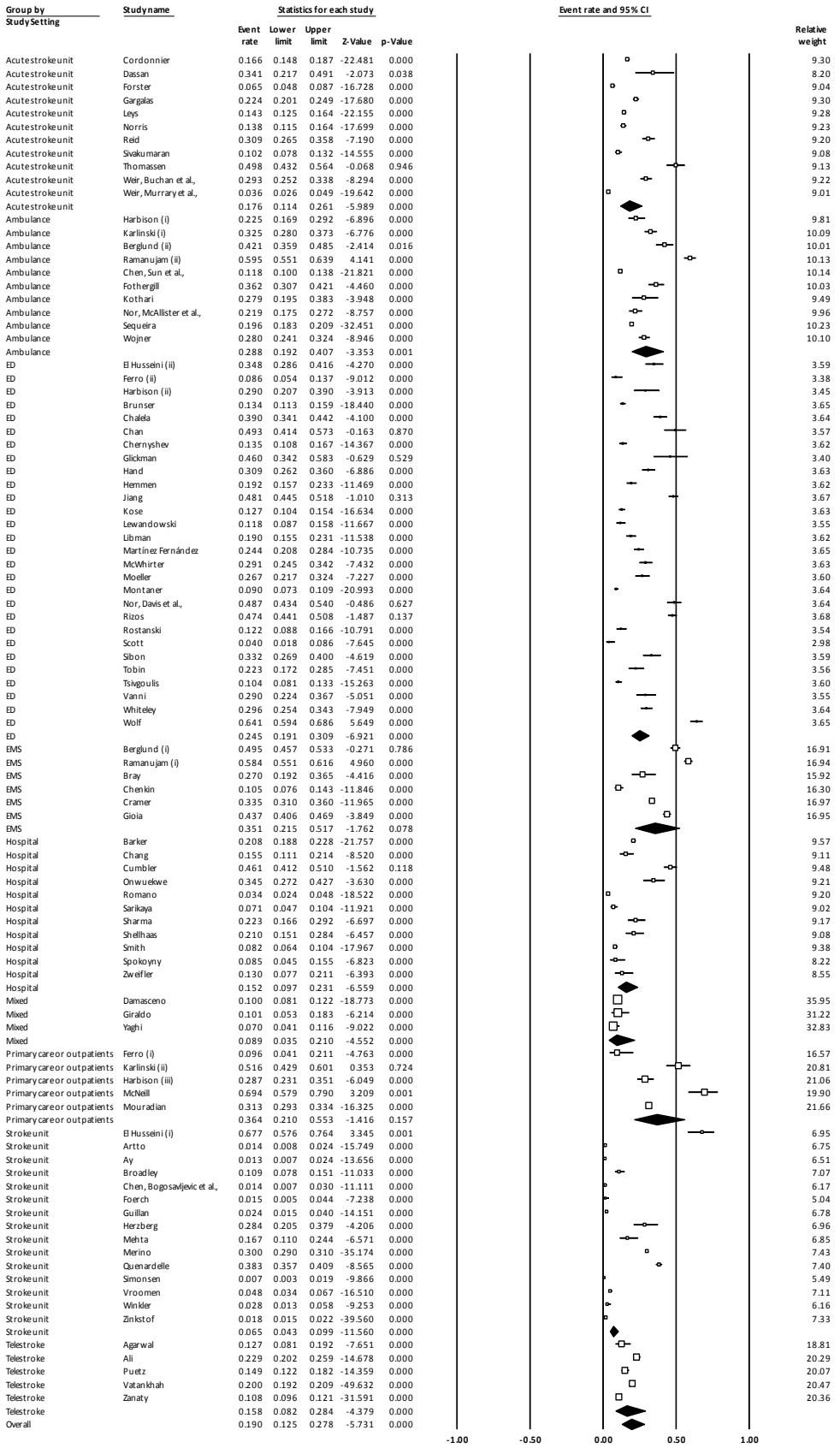

Figure 41 Forest plot displaying the proportion of patients with an eventual stroke mimic diagnosis from medical services. The size of each square is proportional to the weight given to the study in the summary statistics.

Appendix 2.9: Functional stroke mimic forest plot

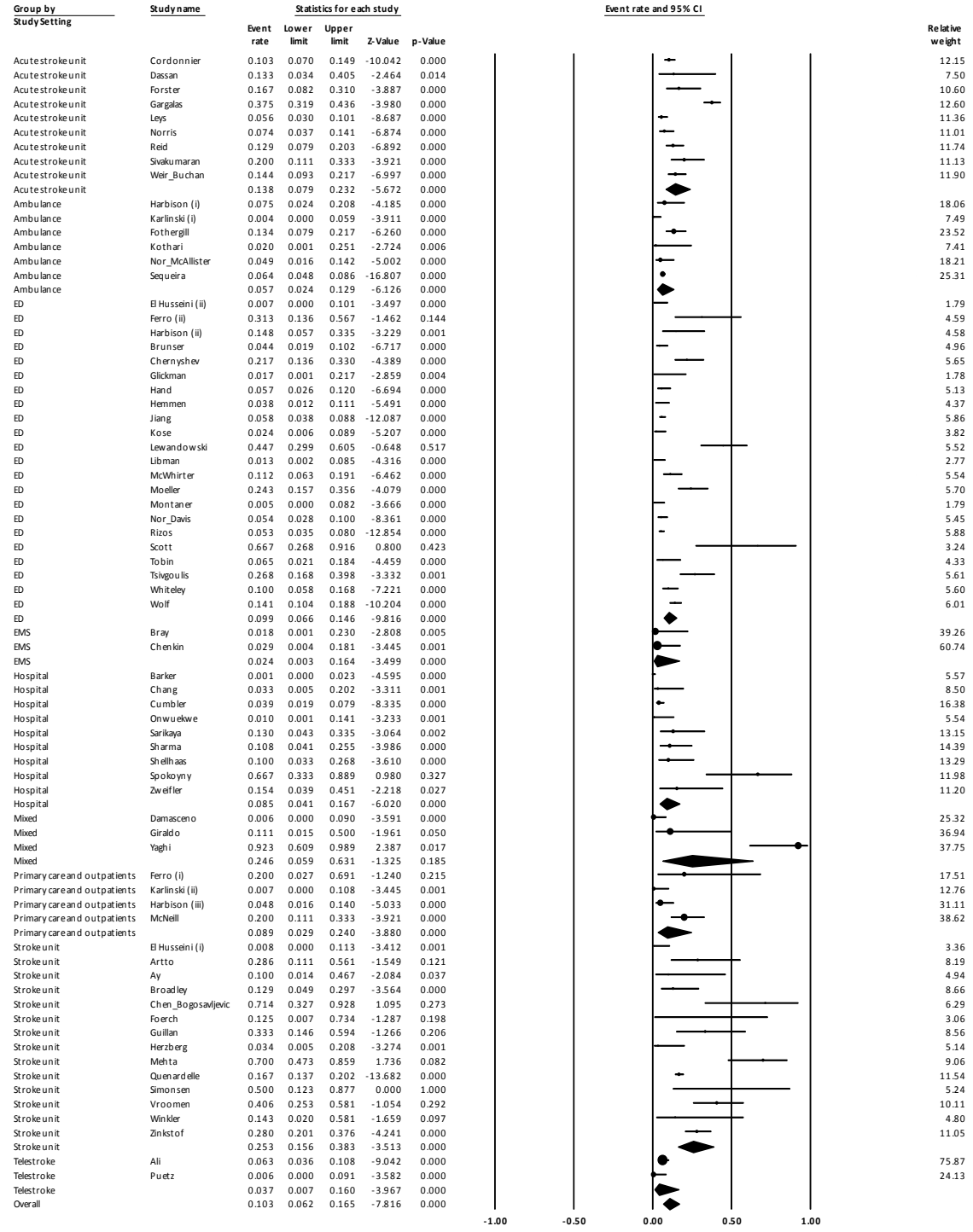

Figure 42 Forest plot displaying the proportion of stroke mimic patients with functional disorder diagnosis by service setting. The size of each square is proportion to the weight given to the study in the summary statistics.

Appendix 3.1: Qualitative survey responses

Table 81 Written survey responses to the question, “Patients with functional stroke symptoms should be managed”

Patients with functional stroke symptoms should be managed:	Participant
"In community where possible"	Female, 39, physiotherapist
"I don't think it is possible to manage them in one (setting). Multiple teams need to work together."	Female, 28, physiotherapist
"Neurology/stroke wards where staff have relevant experience or in specialist rehab units for functional disorders in some particularly challenging cases	Male, 34, physiotherapist
“A setting with access to the correct services - usually PT, psychology, OT etc. - this could be in inpatient setting or at home if possible”	Anonymous
“In mental health with a combination of PT and OT”	Female, 32, clinical psychologist
“Inpatient hospital or GP”	Anonymous
"Variety of settings with physical and psychological management"	Anonymous
"MDT setting with psychiatry and psychology"	Female, 31 physiotherapist
"Dependent on severity. Some can be managed at home and with psychological support and rehab. Others need inpatient"	Female, 33
"Least of all medical/surgical outpatients, probably depends on their needs"	Female, 30, physiotherapist
"A combination of primary care and mental health"	Female, 37, speech and language therapist
"In primary care if symptoms are mild. In mental health if this is the main background issue. In other settings which require a combination of physical and mental health - a holistic approach is essential!"	Female, 52, occupational therapist
"In primary care with mental health support"	Female, 31, physiotherapist
"Joint care from secondary to primary"	Female, stroke/TIA nurse
"Community psychiatry"	Female, 28, SHO
"Functional clinics"	Male, 30, physiotherapist,
“Neurologists with a special interest in functional disease and multidisciplinary team support”	Female, 37, acute medicine consultant
“Need auxiliary in secondary care then direct to appropriate community based management”	Female, 58, allied health professional

Table 82 Written responses to the statement, “There are effective treatments for functional stroke patients”

“There are effective treatments for functional stroke patients”	Participant
“Just not utilised in all cases”	Male, 32, physiotherapist
"Success rates are not 100%!!"	Female, 30, physiotherapist
“Most research is case study based: uncertain effects"	Male, 39, physiotherapist
“Multidisciplinary team approach essential”	Female, 37, consultant

Table 83 Written response to the statement, “Patients with functional stroke symptoms are difficult to manage

“Patients with functional stroke symptoms are difficult to manage”	Participant
“Only because we don’t have special psychiatry/psychology coverage attached to stroke	Female, 40, speech and language therapist

Table 84 Responses to, “Which setting currently provides the most effective treatment?”

Which setting currently provides the most effective treatment for patients with functional stroke symptoms?	Participant
"Complex needs with expertise in functional difficulties with PT and OT"	Female, 32, clinical psychologist
" Depends/variety of settings required”	Anonymous
"Allocated units for FND. Community with specialist therapists and physiotherapy if appropriate”	Female, 30, physiotherapist
“I don't think any setting is particularly effective”	Male, 39, physiotherapy
“Specialist neuro/liaison psychiatry”	Neuropsychiatry consultant, 55
“Functional clinics”	Male, 30, physiotherapist
“This is unknown as there is no pathway to make this clear”	Female, 36, occupational therapist

Table 85 Written responses to the statement, “Patients with functional symptoms have an undiagnosed physical illness”

“Patients with functional symptoms have an undiagnosed physical illness”	Participant
"Sometimes - can't answer this, easily they can”	Female, 30, neuropsychiatrist
"Disagree but there are exceptions”	Female, registrar

Table 86 Written responses to the statement, “Patients with functional stroke symptoms have a psychiatric disorder”

“Patients with functional stroke symptoms have a psychiatric disorder”	Participant
“Some will, some won't”	Female, 52, occupational therapist
"Psychological rather than psychiatric"	Female, 43, consultant
“I understand that functional stroke symptoms are present in many ‘non-functional’ strokes, in addition to patients presenting with purely ‘functional’ symptoms”	Female, 40, speech and language therapist

Table 87 Written responses to the statement, “What is the role of the doctor or health care team in managing functional stroke symptoms?”

What is the role of the doctor or health care team in managing functional stroke symptoms?	Participant
“To signpost”	Female, 43, consultant
“To explain to the patient what is going on”	Female, 37, acute medicine consultant

Table 88 Written responses to the statement, "Physiotherapy could prove an effective treatment for some functional stroke patients"

"Physiotherapy could prove an effective treatment for some functional stroke patients"	Participant
"In combination with mental health/psychology/OT	Anonymous
"In combination with psychology"	Female, 29, neurologist

Table 89 Written responses to the statement, “Patients with functional stroke symptoms have personality disorders”

“Patients with functional stroke symptoms have personality disorders”	Participant
“I think it's 25% of patients not all of them”	Female, 30, occupational therapist
"Some will, some won't. Often see high levels of stress"	Female, 52, occupational therapist
“Sometimes, certainly can be elements”	Female, 30, neuropsychiatrist
“Depends on the patient”	Female, 32, physiotherapist

Table 90 Written response to the statement, "There are clear guidelines on how to manage patients with functional stroke symptoms”

"There are clear guidelines on how to manage patients with functional stroke symptoms”	Participant
“"If you know where they are and who to consult"	Anonymous

Appendix 3.2: Stroke staff questionnaire

KING'S College LONDON

This survey assesses your attitudes and opinions regarding patients with functional or medically unexplained symptoms. It forms part of a study on the feasibility of a physiotherapy trial for functional stroke patients. Participation is voluntary and all information will be treated as private and confidential. Thank you for your participation.

1. Have you ever worked with a patient with functional stroke symptoms?

Yes	No

If yes, please complete the rest of the survey. If no, thank you for your participation.

Please select one answer for each of the following statements:

2. "Patients with functional stroke symptoms are difficult to manage"

Strongly Agree Agree Disagree Strongly Disagree

3. "Patients with functional stroke symptoms have an undiagnosed physical illness"

Strongly Agree Agree Disagree Strongly Disagree

4. "Patients with functional stroke symptoms have personality disorders"

Strongly Agree Agree Disagree Strongly Disagree

5. "Patients with functional stroke symptoms have a psychiatric illness"

Strongly Agree Agree Disagree Strongly Disagree

6. Patients with functional stroke symptoms should be managed:
Please choose one

- In primary care
- In medical/surgical outpatients
- In mental health
- Outside the NHS
- In other settings

Please turn over

7. Which setting currently provides the most effective treatment for patients with functional stroke symptoms:
Please choose one

- Primary care
- Medical/surgical outpatients
- Mental health
- Outside the NHS
- Other settings

8. What is the role of the doctor or health care team in managing functional stroke symptoms?
Please select up to three:

(a) To provide reassurance and support

(b) Not to get too involved in their management

(c) To have no involvement with them at all

(d) To refer for further investigations to identify a cause

(e) To prescribe psychotropic medication

(f) To act as a gatekeeper preventing inappropriate investigation

(g) To provide counselling and appropriate psychological management

9. "Further research is needed into the area of functional stroke symptoms"

Strongly Agree Agree Disagree Strongly Disagree

10. "There are effective treatments for functional stroke patients"

Strongly Agree Agree Disagree Strongly Disagree

11. "Physiotherapy could prove an effective treatment for some functional stroke patients"

Strongly Agree Agree Disagree Strongly Disagree

12. "There are clear guidelines on how to manage patients with functional stroke symptoms"

Strongly Agree Agree Disagree Strongly Disagree

Age:	
Gender:	
Speciality:	
Grade:	

Thank you for your participation.

Appendix 3.3: Information sheet for NHS staff

INFORMATION SHEET FOR NHS STAFF

REC Reference Number: 15/LO/1914

Study Title: The feasibility of a randomised controlled trial study for functional stroke patients in a stroke setting

Dear Sir/Madam

You are invited to take part in a study being carried out at Friend's Stroke Unit, King's College Hospital in conjunction with King's College London.

Purpose of the study

The purpose of this study is to investigate whether it is possible and useful to conduct a future study which would trial and test a physiotherapy intervention for patients with functional or unexplained stroke symptoms.

What the study involves

Taking part in this study involves an interview with a researcher. You will be asked some questions about your views on a possible future study. This future study would examine whether physiotherapy is effective in treating patients with functional stroke symptoms.

The interview will be recorded with an encrypted audio device.

Do I have to take part?

Taking part in this study is entirely voluntary. You do not have to take part and you can withdraw your consent from the study at any time, without giving a reason.

What are the possible risks of taking part?

If you find the interview distressing or uncomfortable at any time, please inform the researcher and the interview can be stopped immediately or completed at a later date.

What are the possible benefits of taking part?

This research will be used to inform the design of a possible treatment for functional stroke patients on stroke wards. If future research is successful, this may mean new treatments are offered to functional stroke patients.

Will my taking part be kept confidential?

Your involvement in this study will be strictly confidential. Only the research team will have access to the information you provide. All information will be held in safe, secure filing cabinets and on secure computer servers operated and managed by King's College London. The information that you provide will not be shared with any person or organisation outside the study team, however the local NHS Research and Development office may request access to monitor the quality of the study.

All data will be stored in line with the Data Protection Act of 1998.

How is the project being funded?

This project is funded by the National Institute of Health Research through the Biomedical Research Centre at King's College London as part of a PhD project.

What will happen to the results of the study?

The results of the study will be analysed and may be published in a peer-reviewed journal. All information will be anonymous and no identifiable information will be published. This study will also form part of a PhD project at King's College London.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

Name: Nicola O'Connell
Email: Nicola.o'connell@kcl.ac.uk
Telephone: 020 7848 0138

What if I have further questions, or if something goes wrong?

If this study has harmed you in any way, if you wish to make a complaint about the conduct of the study or you wish to find out more details about the study, you can contact King's College London using the details below for further advice and information:

Professor Anthony David, 16 De Crespigny Park, London, SE5 8AF

Thank you for reading this information sheet and for considering taking part in this research.

Appendix 3.4: Consent form for NHS staff

CONSENT FORM FOR NHS STAFF

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: The feasibility of a randomised controlled trial study for functional stroke patients in a stroke setting

Rec Ref:15/LO/1914

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at an time.

Please initial

I confirm that I understand that by signing my initials in each box I am consenting to this element of the study. I understand that it will be assumed that uninitialled boxes mean that I DO NOT consent to that part of the study. ☐

Please initial

1. *I confirm that I have read and understood the information sheet dated 02/12/2015 Version Two for the above study. I have had the opportunity to consider the information and asked questions which have been answered satisfactorily. ☐
2. *I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. Furthermore, I understand that I will be able to withdraw my data up to 2 weeks after my interview. ☐
3. *I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 1998. ☐
4. *I understand that my information may be subject to review by responsible individuals from a research and development office for monitoring and audit purposes. ☐
5. *I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications ☐

6. *I agree to be contacted for future studies of a similar nature ☐

7. *I consent to my interview being audio recorded. ☐

8. *I would like to receive a copy of the study's findings. ☐

_____	_____	_____
Name of Participant	**Date**	**Signature**
_____	_____	_____
Name of Researcher	**Date**	**Signature**

Appendix 3.5: Interview schedule for NHS stroke staff

Interview Schedule for NHS Stroke Staff

Introduction

- Researcher introduces herself and outlines the aims of the project – this study aims to explore the views of patients on a possible trial which would take place on the stroke ward. The study is also interested in exploring the experiences of patients on the stroke ward who may have an alternative diagnosis to stroke.

- The study aims to gain an understanding of different views and there are no 'wrong answers'

- The interview should take about 20 minutes and will be recorded to ensure accuracy in the study. All of your answers will be treated with upmost confidentiality and all information that might be published at a later date will be anonymous.

- Consent form.

- Allows the participant to introduce themselves.

- Allows the participant to introduce themselves.

Part One: Experiences with and attitudes towards stroke mimic patients and functional stroke mimic patients

- Can you describe a typical functional stroke mimic presentation is?
- Could you think of an example from the last few weeks?
- How were the symptoms managed?
- Did you order any investigations or referrals?
- What factors did you consider when making this choice?
- What was the outcome?
- Was this example typical of other patients you have seen without a diagnosis of stroke?
- If yes, why? If no, why not?
- What do you believe is the cause of the presentation?
- Do you have any opinion of what the prognosis of these patients is?
- How many functional stroke mimic patients do you treat in a week or a month?

- Can you give an overview of some of your experiences working with stroke mimic patients?
- Can you describe how you diagnose a stroke mimic patient? How do you diagnose a functional stroke mimic patient?
- How does the treatment of a suspected functional stroke mimic patient differ from a stroke patient on the ward, if at all?

- Are there any differences in how you diagnose stroke mimic patients depending on who the consultant or staff on duty are or any occupational issues on the ward, like access to MRI?

- How much are you influenced by the policies or practices of the consultant or team you are working with when you manage these patients? Do any of these issues affect the speed of diagnosis or the speed at which a patient is referred or discharged?

- Do you feel that this varies between different teams that you have worked with?

- How long is a stroke mimic patient likely to stay on the stroke ward? Generally, where are they discharged or referred to? Do you organise follow-up appointments with stroke mimic patients? If not, what are the reasons?

- How easy or difficult do you think it is to treat stroke mimic patients generally and functional stroke mimic patients particularly?

- Have you had any memorable functional stroke mimic cases?

- In an ideal world, how would you treat functional stroke mimic patients on your ward?

- Do you notice any differences in the rate at which stroke mimic patients and functional stroke mimic patients present to the ward? For example, are there certain times of the week or the year where there are higher rates of admissions? Are admission rates affected by events like Christmas or sporting events or do you feel admission rates stay the same throughout the year?

Part Two: Attitudes towards a possible physiotherapy trial at the Friend's Stroke Ward

- My research team is discussing the possibility of providing some kind of physiotherapy trial for patients with functional stroke mimic symptoms. I am interested in how you might feel about such an intervention.

- What do you think might be the advantages and challenges in conducting a trial like this generally and specifically on this ward?

- Do you feel there is a need for research like this, or do you feel there is enough current evidence? If such a trial were to take place, do you think you would be interested in being involved?

Part Three: Rounding Up

- Are there any questions you would like to ask me?

- Is there anything you have said that you would like to retract or anything that you have not said that you would like to add further?

- Thank the participant

Appendix 4.1: Brief Illness Perception Questionnaire

For the following questions, please circle the number that best corresponds to your views:

How much does your illness affect your life?

0	1	2	3	4	5	6	7	8	9	10
no affect at all										severely affects my life

How long do you think your illness will continue?

0	1	2	3	4	5	6	7	8	9	10
a very short time										forever

How much control do you feel you have over your illness?

0	1	2	3	4	5	6	7	8	9	10
absolutely no control										extreme amount of control

How much do you think your treatment can help your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely helpful

How much do you experience symptoms from your illness?

0	1	2	3	4	5	6	7	8	9	10
no symptoms at all										many severe symptoms

How concerned are you about your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all concerned										extremely concerned

How well do you feel you understand your illness?

0	1	2	3	4	5	6	7	8	9	10
don't understand at all										understand very clearly

How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

0	1	2	3	4	5	6	7	8	9	10
not at all affected emotionally										extremely affected emotionally

Appendix 4.2 Information sheet for patients

INFORMATION SHEET FOR PARTICIPANTS

REC Reference Number: 15/LO/1914

Study Title: The feasibility of a randomised controlled trial study for functional stroke patients in a stroke setting

Dear Sir/Madam

You are invited to take part in a study being carried out at Friend's Stroke Unit, King's College Hospital in conjunction with King's College London.

Purpose of the study

The purpose of this study is to investigate whether it is possible and useful to conduct a future study using physiotherapy for patients with functional or unexplained stroke symptoms.

What the study involves

Taking part in this study involves a short interview with a researcher. The interview should take no longer than 20 minutes. You will be asked some questions about your experiences at Friend's Stroke Unit and about your views and opinions on a possible future study. This future study would examine whether physiotherapy is effective in treating patients with functional stroke symptoms.

You are also invited to take part in a follow-up interview two months after the first interview. The purpose of this is to examine whether your views or opinions have changed. Deciding to take part in a second interview is entirely optional and you can change your mind at any time.

Both interviews will be recorded with an encrypted audio device.

Do I have to take part?

Taking part in this study is entirely voluntary. You do not have to take part and you can withdraw your consent from the study at any time, without giving a reason.

What are the possible risks of taking part?

Some participants might find it distressing to discuss their symptoms. If you find the interview upsetting or uncomfortable at any time, please inform the

researcher and the interview can be stopped immediately or completed at a later date.

What are the possible benefits of taking part?

Participants in research often find it beneficial to talk to people outside their care team about their experiences. By taking part in this study, you are contributing to important research. This research will be used to inform the design of a possible treatment for patients on stroke wards. If future research is successful, this may mean new treatments are offered to patients, which may, in the long term, directly benefit patients.

Will my taking part be kept confidential?

Your involvement in this study will be strictly confidential. Only the research team will have access to the information you provide. All information will be held in safe, secure filing cabinets and on secure computer servers operated and managed by King's College London. The information that you provide will not be shared with any person or organisation outside the study team however the local NHS Research and Development office may request access to monitor the quality of the study.

All data will be stored in line with the Data Protection Act of 1998.

How is the project being funded?

This project is funded by the National Institute of Health Research through the Biomedical Research Centre at King's College London as part of a PhD project.

What will happen to the results of the study?

The results of the study will be analysed and may be published in a peer-reviewed journal. All information will be anonymous and no possible identifiable information will be published. This study will also form part of a PhD project at King's College London.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me at: email: Nicola.o'connell@kcl.ac.uk telephone: 020 7848 0138

If you would like any more information about functional symptoms, neurosymptoms.org is a useful website with more details on symptoms and treatments.

What if I have further questions, or if something goes wrong?

If this study has harmed you in any way, if you wish to make a complaint about the conduct of the study, or you wish to find out more information about the study, you can contact King's College London using the details below for further advice and information:
Professor Anthony David, 16 De Crespigny Park, London, SE5 8AF

The Patient Advice and Liaison Service (PALS) at King's College Hospital offers support, information and assistance to patients. Their contact details are:

Telephone: 020 3299 3601 Email: kch-tr.PALS@nhs.net

Thank you for reading this information sheet and for considering taking part in this research.

Appendix 4.3: Consent sheet for patients

CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: The feasibility of a randomised controlled trial study for functional stroke patients in a stroke setting

Rec Reference: 15/LO/1914

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at ar time.

Please initial

I confirm that I understand that by signing my initials in each box I am consenting to this element of the study. I understand that it will be assumed that uninitialled boxes mean that I DO NOT consent to that part of the study.

Please initial

9. *I confirm that I have read and understood the information sheet dated 2nd December 2015, Version Two for the above study. I have had the opportunity to consider the information and asked questions which have been answered satisfactorily.
10. *I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. Furthermore, I understand that I will be able to withdraw my data up to 2 weeks after my interview.
11. *I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 1998.
12. *I consent to the interview taking place at my bedside.
13. *I consent to the interview taking place in a private room on the ward.
14. *I understand that my information may be subject to review by responsible individuals from a research and development office for monitoring and audit purposes.

15. *I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications ☐

16. *I agree to be contacted in two months' time by a King's College London researcher who would like to invite me to participate in a follow-up interview ☐

17. *I agree to be contacted for future studies of a similar nature ☐

18. *I consent to my interview being audio recorded ☐

19. *I would like to receive a copy of the study's findings. ☐

_____	_____	_____
Name of Participant	**Date**	**Signature**

_____	_____	_____
Name of Researcher	**Date**	**Signature**

Appendix 4.4: Interview schedule for patients

Interview Schedule for patients

Introduction

- Researcher introduces herself and outlines the aims of the project.
- Allows the participant to introduce themselves.

Part One: Background to admission

- Can you tell me about the lead up to your admission at the Friend's Stroke Unit?
- What type of symptoms did you experience?
- How were you admitted to the hospital? Were you referred from another hospital, for example, or did you arrive by ambulance?
- How did you feel at the time of your admission?

Part Two: History and experience of symptoms

- Can you tell me about your symptoms? How long have you experienced these symptoms? Is this the first time you have experienced such symptoms or has this happened before?
- Have you had previous treatment or is this the first time?
- Do these symptoms affect your day-to-day living, and if so, how?
- Did you (or do you) take any measures to prevent these symptoms – for example through treatment or in your day-to-day life?

Part Three: Illness beliefs and attitudes

- Are these symptoms something you feel you can or might be able to control or do you feel they beyond your control?
- How did you feel when you first experienced these symptoms? How do you feel now? If there is a difference, what do you think contributed to that difference?
- What did the doctors on the ward tell you about your symptoms? How do you feel about what they have told you?
- Can you think of anything that might help you with these symptoms in the future? Any service or type of care that you feel is not currently offered?

Part Four: Attitudes to a physical therapy trial

- My research team is discussing the possibility of providing some kind of physiotherapy trial for patients with the same symptoms as you. I am interested in how you might feel about such an intervention.
- Would you be interested in taking part in a research study that meant you received physiotherapy?
- Would you be willing to participate in randomised trial where there is a chance you might be randomised to a control group?
- Would you be willing to travel to take part? If so, how far would you be willing to travel?
- Would you prefer that such an intervention was provided locally to you or would this hospital be a convenient setting for you?
- On a scale of one to ten, with one meaning not at all interested and ten meaning extremely interested, how would you rate your interest in such a trial?

- If you had to wait for this physiotherapy (on a study waiting list), perhaps for two or three months, would you still be willing to take part?
- What are the main reasons you would decide to join (or not interested: not to join?
- Sometimes in these studies, there is a control group. If you were allocated to this group it might mean you received no treatment but we might still visit you and ask you questions. Would you still be interested in taking part if this happened?
- If there was a choice in the type of intervention that you received, would you have a preference? (Different examples include learning relaxation techniques, breathing exercises) What are the reasons you might prefer one such intervention over another?

Part Five: Rounding Up

- Finally, how do you view the future?
- Are there any questions you would like to ask me?
- Is there anything you have said that you would like to retract or anything that you have not said that you would like to add further?

- Thank the participant

Appendix 5.1: CRIS search criteria

First search: F44.4 in primary diagnosis yielding 176 results.

CRIS code: (Assmnts.Diagnosis.Primary_Diag="F44.4 - Dissociative motor disorders")

Second search: “Functional Motor”, “Dissociative Motor”, “Psychogenic Motor”: free text search in ‘Events and Correspondence’ yielding 167 results.

CRIS code: (Events.Event.Comments=""Dissociative motor"") OR (Events.Event.Comments=""Functional motor"") OR (Events.Event.Comments=""Psychogenic motor"") OR (Correspondence.Attachment.Attachment_Text=""Psychogenic motor"") OR (Correspondence.Attachment.Attachment_Text=""Functional motor"") OR (Correspondence.Attachment.Attachment_Text=""Dissociative motor"")

Third search: F44.7 AND ((“motor” in events) OR (“motor” in correspondence)) yielding 60 results

CRIS code: (Assmnts.Diagnosis.Primary_Diag="F44.7 - Mixed dissociative [conversion] disorders") AND ((Events.Event.Comments="Motor") OR (Correspondence.Attachment.Attachment_Text="Motor"))

Fourth search: F44.4 in secondary diagnosis, yielding 12 results.

CRIS code: (Assmnts.Diagnosis.Secondary_Diag_1="F44.4")

Fifth search: F44.7 in secondary diagnosis AND ((“motor” in events) OR (“motor” in correspondence)), yielding 9 results

CRIS code: (Assmnts.Diagnosis.Secondary_Diag_1="F44.7") AND ((Events.Event.Comments="Motor") OR (Correspondence.Attachment.Attachment_Text="Motor"))

Sixth search: Free-text search of “motor conversion disorder” yielding 10 results

Seventh search: Free-text search of “motor conversion” yielding 13 results

Eight search: Search of “F44” in primary diagnosis and free-text search of “motor” in events, yielding 77 results

CRIS code: Assmnts.Diagnosis.Primary_Diag="F44 - Dissociative [conversion] disorders") AND (Events.Event.Comments="Motor")

Ninth search: Search of “F44” in primary diagnosis field and free-text search of “weak” in events”, yielding 155 results

CRIS code: (Assmnts.Diagnosis.Primary_Diag="F44 - Dissociative [conversion] disorders") AND (Events.Event.Comments="weak")

Appendix 5.2: Main diagnoses given in CRIS for FMD and control group patients

Table 91 The number and frequency of SLaM diagnoses given across time to FMD and control group

	Main SLaM diagnosis		Secondary SLaM diagnosis		Tertiary SLaM diagnosis	
	FMD n (%)	Control group n (%)	FMD n (%)	Control group n (%)	FMD n (%)	Control group n (%)
ICD-10 Diagnosis						
(F00-F09) Organic mental disorders	7 (2.2)	5 (0.8)	5 (2.7)	15 (2.9)	1 (1.4)	12 (4.1)
(F10-F19) Mental & behavioural disorders due to psychoactive substances	3 (0.9)	112 (17.4)	2 (1.1)	92 (17.8)	1 (1.4)	52 (17.7)
(F20 – F29) Schizophrenia, schizotypal and delusional disorders	4 (1.2)	90 (14)	3 (1.6)	95 (18.3)	6 (8.1)	47 (16)
(F30 – F39) Mood disorders	22 (6.8)	146 (22.7)	10 (5.4)	130 (25.1)	5 (6.8)	65 (22.2)
(F40 – F48) Neurotic, stress & somatoform disorders	185 (57.5)	70 (10.9)	139 (75.5)	62 (12)	49 (66.2)	33 (11.3)
(F50 – F59) Behavioural syndromes associated with physiological disturbances	2 (0.6)	17 (2.6)	1 (0.5)	9 (1.7)	1 (1.4)	2 (0.7)
(F60 – F69) Disorders of adult personality and behaviour	4 (1.2)	12 (1.9)	4 (2.2)	25 (4.8)	2 (2.7)	25 (8.5)
(F70 – F79) Intellectual disabilities	0 (0)	1 (0.2)	1 (0.5)	0 (0)	0 (0)	0 (0)
(F80 – F89) Disorders of psychological development	0 (0)	2 (0.3)	0 (0)	3 (0.6)	0 (0)	2 (0.7)
(F90 – F98) Behavioural and emotional disorders with onset in in childhood and adolescence	0 (0)	14 (2.2)	1 (0.5)	11 (2.1)	0 (0)	3 (1)
(F99) Unspecified mental disorder	41 (12.7)	73 (11.3)	7 (3.8)	37 (7.1)	2 (2.7)	31 (10.6)
Other Diagnoses						
(FXX)	9 (2.8)	4 (0.6)	4 (2.2)	1 (0.2)	0 (0)	0 (0)
No axis one disorder	0 (0)	3 (0.5)	0 (0)	2 (0.4)	0 (0)	0 (0)
(Z00 – Z99) Factors influencing health status and contact in health services	38 (11.8)	89 (13.8)	3 (1.6)	31 (6)	5 (6.8)	21 (7.2)
(F00-F99) Mental, behavioural & neurodevelopmental disorders	2 (0.6)	2 (0.3)	3 (1.6)	5 (1)	1 (1.4)	0 (0)
(G00-G99) Diseases of the nervous system	2 (0.6)	0 (0)	1 (0.5)	0 (0)	1 (1.4)	0 (0)
(M00-M99) Diseases of the musculoskeletal system	2 (0.6)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
(B20 – B24) HIV	0 (0)	1 (0.2)	0 (0)	0 (0)	0 (0)	0 (0)
(X60 – X84) Intentional self-harm	0 (0)	1 (0.2)	0 (0)	0 (0)	0 (0)	0 (0)
(R00-R09) Symptoms, signs and abnormal clinical and lab findings	1 (0.3)	2 (0.3)	0 (0)	0 (0)	0 (0)	0 (0)
Total	322 (100)	644 (100)	184 (100)	518 (100)	74 (100)	293 (0)

Appendix 5.3: List of teams giving first SLaM diagnoses

Table 92 List of teams giving first SLaM diagnoses to FMD and control groups

	Functional motor disorder n (%)	Control group n (%)	χ^2	95% CI	*p* value
Neuropsychiatry (psychiatric and general) hospital outpatients	79 (39.9)	1 (0.4)	108	32.4 – 46.7	**0.001**
Neuropsychiatry liaison service - general hospital inpatients	35 (17.7)	0 (0)	43.9	12.4 – 23.7	**0.001**
Liaison psychiatry – inpatients	25 (12.6)	46 (20.2)	4.4	0.2 – 14.8	**0.04**
Lishman inpatient ward	23 (11.6)	1 (0.4)	25	6.7 – 16.5	**0.001**
Liaison psychiatry – outpatients	7 (3.5)	3 (1.3)	2.3	-1 – 5.9	0.13
Department of Psychological Medicine	5 (2.5)	0 (0)	5.8	0.17 – 5.8	**0.02**
Brain Injury outpatients	4 (2)	0 (0)	4.6	-0.2 – 5.1	**0.03**
General hospital outpatients	4 (2)	2 (0.9)	0.92	-1.6 – 4.2	0.34
Liaison psychiatry -unspecified	2 (1)	0 (0)	2.3	-0.8 – 3.6	0.13
Chronic Fatigue service	2 (1)	2 (0.9)	0.01	-2.3 – 2.8	0.92
Mood, anxiety and personality services (MAP) and anxiety disorders outpatient service	2 (1)	16 (7)	9.4	2.1 – 10.2	**0.002**
Child and adolescent services	2 (1)	1 (0.4)	0.6	-1.5 – 3.2	0.45
A&E	2 (1)	34 (14.9)	26.4	8.8 – 19.3	**0.001**
Psychiatric hospital - inpatients	2 (1)	0 (0)	2.3	-0.8 – 3.6	0.13
ADHD services	1 (0.5)	9 (3.9)	5.4	0.3 – 6.8	**0.02**
Community mental health teams	1 (0.5)	6 (2.6)	2.9	-0.7 – 5.1	0.09
OCD services	1 (0.5)	1 (0.4)	0.02	-1.9 – 2.4	0.87
Drug and alcohol intervention services	1 (0.5)	25 (11)	20.3	6.1 – 15.3	**0.001**
General hospital – inpatients	0 (0)	5 (2.2)	4.4	-0.16 – 5.1	**0.04**
Eating disorder services	0 (0)	6 (2.6)	5.2	0.12 – 5.6	**0.02**
Older adults services	0 (0)	9 (3.9)	7.9	1.1 – 7.3	**0.005**
Crisis resolution and home treatment teams and home treatment teams	0 (0)	5 (2.2)	4.4	-0.16 – 5.1	**0.04**
Assessment and liaison neighbourhood teams and assessment and brief treatment teams	0 (0)	25 (11)	23.1	6.8 – 15.8	**0.001**
Homeless outreach	0 (0)	2 (0.9)	0.18	-1.8 – 1.8	0.67
Integrated memory services	0 (0)	3 (1.3)	2.6	-0.8 – 3.8	0.11
Psychotherapy outpatients/integrated psychological therapy service	0 (0)	6 (2.6)	5.2	0.13 – 5.6	**0.02**
Maternal and perinatal mental health services	0 (0)	9 (3.9)	7.9	1.1 – 7.3	**0.005**
Early intervention	0 (0)	3 (1.3)	2.6	-0.8 – 3.8	0.11
Couple and sexual services	0 (0)	3 (1.3)	2.6	-0.8 – 3.8	0.11
Criminal justice services	0 (0)	1 (0.4)	0.80	-1.5 – 2.4	0.40
Behavioural genetics	0 (0)	3 (1.3)	2.6	-0.8 – 3.8	0.11
HIV mental health services	0 (0)	1 (0.4)	0.80	-1.5 – 2.4	0.40
Total	198 (100)	228 (100)			
Not known	124 (38.5)	416 (64.6)	28.9	16.4 – 35.3	**0.001**

Appendix 5.4: Employment rates categorised according to ISCO-08 criteria

Table 93 Employment rates in functional motor and control groups according to the International Standard Classification of Occupations (ISCO-08)

	Functional motor disorder n (%)	Control group n (%)	$\chi 2$	95% CIs	*p* value
Armed forces (skill level 1, 2, 4)	2 (0.8)	3 (0.08)	2	-0.6 – 2.9	> 0.05
Female	0 (0)	1 (33.3)			
Male	2 (100)	2 (66.6)			
Managers (skill level 3, 4)	7 (2.95)	13 (3.6)	0.18	-2.8 – 3.7	> 0.05
Female	6 (85.7)	3 (23.1)			
Male	1 (14.3)	10 (76.9)			
Professionals (skill level 4)	50 (21.1)	71 (19.8)	0.15	-5.4 – 8.3	> 0.05
Female	42 (84)	47 (66.2)			
Male	8 (16)	24 (33.8)			
Technicians and associate professionals (skill level 3)	47 (19.8)	41 (11.5)	7.8	2.1 – 14.8	**0.005**
Female	31 (66.6)	24 (58.5)			
Male	16 (33.3)	17 (41.5)			
Clerical support workers (skill level 2)	24 (10.1)	31 (8.7)	0.3	-3.5 – 6.7	> 0.05
Female	22 (91.6)	25 (80.6)			
Male	2 (9.1)	6 (19.4)			
Service and sales workers (skill level 2)	76 (32.1)	111 (31)	0.1	-6.7 – 9	> 0.05
Female	61 (25.7)	73 (65.8)			
Male	15 (19.7)	38 (34.2)			
Skilled agricultural, forestry and fishing workers (skill level 2)	1 (0.4)	1 (0.3)	0.04	-1.2 – 2	> 0.05
Female	0 (0)	0 (0)			
Male	1 (100)	1 (100)			
Craft related trades workers (skill level 2)	10 (4.2)	22 (6.1)	1	-2.2 – 5.6	> 0.05
Female	0 (0)	3 (13.6)			
Male	10 (100)	19 (86.4)			
Plant and machine operators (skill level 2)	6 (2.5)	27 (7.5)	6.8	1.2 – 8.6	**0.01**
Female	0 (0)	4 (14.8)			
Male	6 (100)	23 (85.2)			
Elementary occupations (skill level 1)	14 (5.9)	38 (10.6)	3.9	-0.1 – 9.2	**0.05**
Female	11 (78.6)	15 (39.5)			
Male	3 (21.4)	23 (60.5)			
Total	237 (100)	358 (100)			

Skill level 1: performance of simple and routine tasks
Skill level 2: performance of tasks which involve the operating of machinery and equipment and require the ability to read information & make written records of work and simple arithmetical calculations
Skill level 3: performance of complex technical and practical tasks that require an extensive body of factual, technical and procedural knowledge in a specialised field, requires high literacy and numeracy and well-developed inter-personal skills
Skill level 4: requires complex problem solving, decision making and creativity based on an extensive body of theoretical and factual knowledge in a specialised field including analysis and research to extend the body of human knowledge in a field, diagnosis and treatment of disease, imparting knowledge to others and designing structures and machinery and processes of construction and production

Appendix 5.5: Rate of diseases in functional motor and control groups

Table 94 Rate of disease in functional motor and control group patients

	Functional motor disorder n (%)	Control group n (%)
A00-B99 Certain infectious and parasitic diseases	**10 (2.3)**	**47 (6.7)**
(A00-A79, B15-B19) Bacterial infections, and other intestinal infectious diseases, STDs and viral hepatitis	5 (50)	30 (66.7)
(B20) HIV Disease	2 (20)	14 (31.1)
(B35-B64) Infections caused by fungi, protozoans, worms and infestations	3 (30)	3 (2.2)
C00-D49 Neoplasms	**15 (3.4)**	**32 (4.6)**
(C00-C96) Malignant Cancer (new or old)	9 (60)	23 (74.2)
(D00-D49) Benign neoplasms	6 (40)	9 (25.8)
D50-D89 Diseases of the blood and blood-forming organs; and certain behaviours involving the immune mechanism	**15 (3.4)**	**16 (2.1)**
E00-E89 Endocrine, nutritional and metabolic diseases	**74 (16.7)**	**104 (15.6)**
(E00-E07) Disorders of the thyroid gland	12 (16.2)	18 (17.3)
(E08-E16) Diabetes mellitus and other disorders of glucose regulation and pancreatic internal secretion	21 (28.4)	38 (36.5)
(E20-E35) Disorders of endocrine gland (excluding PCOS)	2 (2.7)	1 (1)
(E28.2) Polycystic ovarian syndrome	9 (12.2)	2 (1.9)
(E50-E64) Nutritional deficiencies	6 (8.1)	3 (2.9)
(E65-E68) Obesity	1 (1.4)	10 (9.6)
(E70 –E88) Metabolic disorders (excluding high cholesterol)	3 (4.1)	9 (8.7)
(E78) High cholesterol	20 (27)	23 (22.1)
G00-G99 Diseases of the nervous system	**107 (15)**	**48 (7)**
(G20-G26, G30-G32) Extrapyramidal and movement disorders and other degenerative diseases	1 (1.5)	7 (15.2)
(G35-G37) Demyelinating diseases of the central nervous system	3 (4.4)	4 (8.7)
(G40) Epilepsy	15 (22)	11 (23.9)
(G40-G47) “Non-specific seizures”	3 (7.4)	5 (6.5)
(G43) Headache	66 (36.8)	7 (15.2)
(G45) Transient cerebral ischaemic attacks	2 (2.9)	3 (6.5)
(G47) Sleep disorder	2 (2.9)	1 (2.2)
(G50-G59) Nerve, nerve root and plexus disorders	3 (4.4)	3 (6.5)
(G60-G65) Polyneuropathies and other disorders of the peripheral nervous system	1 (1.4)	6 (13)
(G70-G73) Diseases of myoneural junction and muscles	2 (2.9)	0 (0)
(G80-G83) Cerebral palsy and other paralytic syndromes	4 (5.9)	0 (0)
(G89-G99) Other disorders of the nervous system	5 (7.4)	1 (2.2)
H00-H59 Diseases of the eye and adnexa	**5 (1.1)**	**6 (0.9)**
H60-H95 Diseases of the ear and mastoid process	**4 (0.9)**	**6 (0.9)**
I00-I99 Disease of the circulatory system	**60 (13.6)**	**105 (15.7)**
(I05-I09) Chronic rheumatic heart diseases	0 (0)	2 (1.9)
(I10-I16) Hypertensive diseases	22 (36.7)	48 (45.7)
(I20-I25) Ischemic heart diseases	13 (21.7)	15 (14.3)
(I26-I28) & (I30-I52) Pulmonary heart disease, diseases of pulmonary circulation and other forms of heart disease	9 (15)	13 (12.4)
(I60-I69) Cerebrovascular diseases	13 (21.7)	15 (14.3)
(I70-I99) Diseases of arteries, arterioles, capillaries, veins, lymphatic vessels and lymph nodes and unspecified disorders of circulatory system	3 (5)	12 (11.4)

Table 95 Rate of disease in functional motor and control group patients

	Functional motor disorder n (%)	Control Group n (%)
J00-J99 Diseases of the respiratory system	**41 (9)**	**70 (10.5)**
(J00-J22) Acute upper respiratory infections, influenza and pneumonia and other acute lower respiratory infections	0 (0)	4 (5.7)
(J40-J47) Chronic lower respiratory diseases (excluding asthma)	8 (17.5)	20 (28.6)
(J45) Asthma	33 (82.5)	44 (62.9)
(J80-J94) Other diseases of pleura and respiratory system	0 (0)	2 (2.9)
K00-K95 Diseases of the digestive system	**37 (8.1)**	**69 (10.5)**
(K00-K14) Disease of oral cavity, salivary glands and jaws	0 (0)	2 (2.9)
(K20-K38) Diseases of oesophagus, stomach, duodenum and appendix	13 (36.1)	14 (20)
(K40-K46) Hernia	3 (5.6)	10 (14.3)
(K50-K68) Non-infective enteritis, colitis, other diseases of intestines and peritoneum	16 (44.4)	15 (22.9)
(K70-K77) Diseases of liver	2 (5.6)	15 (21.4)
(K80-K95) Disease of gallbladder, biliary tract, pancreas and other diseases of the digestive system	3 (8.3)	13 (18.6)
L00-L99 Diseases of the skin and subcutaneous tissue	**19 (4.3)**	**31 (4.6)**
M00-M99 Diseases of the musculoskeletal system and connective tissue	**36 (8.1)**	**75 (11.2)**
(M05-M19) Inflammatory polyarthropathies and osteoarthritis	13 (36.1)	31 (41.3)
(M20-M27) Other joint disorders and dentofacial anomalies	2 (5.6)	3 (4)
(M30-M49) Systemic connective tissue disorders, deforming dorsopathies, spondylopathies	10 (27.8)	5 (6.7)
(M50-M79) Other dorsopathies and other soft tissue disorders	9 (25)	31 (41.3)
(M80-M94) Disorders of bone density and structure, other osteopathies, chondropathies	2 (5.6)	5 (6.7)
N00-N99 Diseases of the genitourinary system	**31 (7)**	**31 (4.2)**
(N10-N39) Glomerular diseases, renal tublo-interstital diseases, acute kidney failure, chronic kidney disease, urolithiasis, other diseases of kidney and ureter and of the urinary system	13 (41.9)	18 (53.6)
(N40-N53) Diseases of male genital organs	1 (3.2)	6 (21.4)
(N60-N98) Disorders of breast, inflammatory diseases of female pelvic organs and non-inflammatory disorders of female genital tract	17 (54.8)	7 (25)
Q00-Q99 Congenital malformations, deformations and chromosomal abnormalities	**12 (2.7)**	**1 (0.15)**
R00-R99 Symptoms, signs and abnormal clinical and lab findings, not otherwise classified	**16 (3.6)**	**31 (4.2)**
(R03) Abnormal blood pressure reading	5 (31)	8 (28.6)
(R00-R94) Symptoms, signs and abnormal clinical findings (excluding blood pressure), abnormal findings on examination of blood and diagnostic imaging	11 (69)	23 (71.4)
S00-S99 Injuries as a consequence of external cause	**1 (0.2)**	**7 (1)**
Total	**483 (100)**	**679 (100)**

Table 96 Breakdown of types of congenital malformations, deformations and chromosomal abnormalities for functional motor and control group patients

	Functional motor group n (%)	Control group n (%)
Congenital malformations, deformations and chromosomal abnormalities	12 (2.7)	1 (0.15)
Female	12 (100)	1 (100)
Mean age	44.3 (14)	43
(Q20-Q28) Congenital malformations of the circulatory system	3	0
Female	3 (0)	0 (0)
Mean age	50.6 (17)	-
(Q65-Q64) Congenital malformations of the urinary system	7	0
Female	7 (100)	0 (0)
Mean age	41.3 (14)	-
(Q80-Q89) Other congenital malformations	2	1
Female	2 (100)	1 (100)
Mean age	45 (4)	43

Table 97 Rate of tuberculosis, hepatitis, HIV and mycoses and protozoal disease in the functional motor and control groups.

	Functional motor group n (%)	Control group n (%)
A15 – A69 (Tuberculosis, other bacterial disease, infections with a predominantly sexual mode of transmission and other spirochetal diseases)	2 (20)	4 (8.9)
Female	1 (50)	1 (25)
Mean age	48 (8.5)	73.8 (14)
B15 – B19 (Viral hepatitis)	3 (30)	26 (55.3)
Female	1 (33.3)	7 (26.9)
Mean age	56.7 (21.4)	47.6 (NK)
B20 – B20 (Human immunodeficiency virus disease)	2 (20)	14 (29.8)
Female	0 (0)	5 (35.7)
Mean age	45.5 (14.8)	46.3 (NK)
B35 – B64 (Mycoses and protozoal diseases)	3 (30)	2 (4.3)
Female	3 (100)	1 (50)
Mean age	53.3 (20.6)	44.5 (12)

Appendix 5.6: History of familial mental health issues

Table 98 Table showing breakdown of familial mental health issues according to group and relative type

	Functional motor disorder n (%)	Control group n (%)	OR	95% CI	*p* value
History of familial mental health issues [1]	125 (52.1)	197 (60)	0.73	0.5 - 1	> 0.05
Not known	82 (25.5)	315 (49)			
Mean number of relatives with mental health problems (SD)[2]	1.59 (0.9)	1.71 (1)		- 0.3 – 0.8	> 0.05
Relative type					
Mother[3]	55 (30.4)	83 (29.1)	1.1	0.7 – 1.7	> 0.05
Father[4]	33 (18.2)	57 (20)	0.9	0.5 – 1.5	> 0.05
Son, one or more[4]	11 (6.1)	13 (4.6)	1.3	0.5 – 3	> 0.05
Daughter, one or more[4]	7 (3.9)	11 (3.9)	0.96	0.4 – 2.6	> 0.05
Sister, one or more[4]	27 (14.9)	40 (14.1)	1.01	0.6 -1.8	> 0.05
Brother, one or more[4]	21 (11.6)	38 (13.3)	0.8	0.4 – 1.6	> 0.05
Second degree relative, one or more[4]	27 (14.9)	43 (15.1)	0.9	0.5 – 1.7	> 0.05
Total	181 (100)	285 (100)			

[1] History of familial mental health versus no history of familial mental health issues
[2] Independent sample t-test
[3] Reference group: all other relatives with mental health issues
[4] Reference group: mothers with mental health issues

Appendix 5.7: Socio-demographic differences between groups with and without complete HoNOS scores

Table 99 Socio-demographic differences in functional motor and control group patients with two complete HoNOS scores versus patients with one or no complete HoNOS scores

		Two complete HoNOS scores n (%)	One or no complete HoNOS scores n (%)	χ2	95% CI	*p* value
Functional motor group		69 (21.4)	253 (78.6)	79.2	44.4 – 67.4	**0.001**
Gender	Female	52 (75.4)	186 (73.5)	0.10	-11.1 – 13.1	> 0.05
	Male	17 (24.6)	67 (26.5)			
Ethnicity	British	29 (42)	166 (65.6)	12.6	9.6 – 36.8	**0.0004**
	Other ethnicity	40 (58)	87 (34.4)			
CSA	Experienced CSA	10 (19.6)	40 (20.1)	0.008	-11.8 – 10.7	> 0.05
	Didn't experience CSA	41 (80.4)	159 (79.9)			
Work	Employed	12 (17.6)	61 (26.5)	2.3	-3.4 – 18.9	> 0.05
	Unemployed	49 (72.1)	130 (56.5)			
Health	Physical health condition	46 (67.6)	173 (76.5)	0.72	-14 – 27.7	> 0.05
	No physical health condition	22 (32.4)	53 (23.5)			
Control group		320 (49.6)	324 (50.3)	0.03	-7.2 – 8.6	> 0.05
Gender	Female	174 (54.4)	167 (51.5)	0.54	-5 – 10.8	> 0.05
	Male	146 (45.6)	157 (48.5)			
Ethnicity	British	158 (49.4)	170 (52.5)	0.62	-4.8 – 11	> 0.05
	Other ethnicity	162 (50.6)	154 (47.5)			
CSA	Experienced CSA	54 (23.9)	31 (19.3)	2	-2 – 11.1	> 0.05
	Didn't experience CSA	172 (76.1)	130 (80.7)			
Work	Employed	48 (15.2)	56 (19.9)	2.45	-1.4 – 10.8	> 0.05
	Unemployed	236 (74.9)	153 (54.4)			
Health	Physical health condition	167 (58)	159 (61.4)	0.65	-5.1 – 11.8	> 0.05
	No physical health condition	121 (42)	100 (38.6)			

CSA = childhood sexual abuse

Appendix 5.8: Logistic regression results

Table 100 Binary logistic regression model showing the relationship between independent variables and the likelihood of a functional motor patient having a comorbid functional disorder

Variable	B	SE	Wald	OR	*p* value
Female	0.23	0.45	0.25	1.3	0.62
Ethnicity	0.13	0.41	0.10	1.1	0.75
Marital status	0.10	0.40	0.06	1.1	0.80
Previous psychiatric inpatient stay	0.70	0.40	3.3	2	0.07
Patient has carer	0.25	0.40	0.42	0.52	1.3
Employed	-0.19	0.51	0.15	0.82	0.70
Health or social care worker	0.25	0.50	0.25	1.3	0.61
Smoker	0.16	0.38	0.17	1.2	0.68
Experienced CSA	-0.02	0.46	0.002	0.98	0.96
Physical health problem	-0.84	0.44	3.7	0.43	0.054

CSA: childhood sexual abuse

Table 101 Binary logistic regression model showing relationship between independent variables and the likelihood of a psychiatric inpatient admission

Variable	B	SE	Wald	OR	*p* value
Female	-0.15	0.69	0.05	0.86	0.83
British	0.21	0.55	0.15	1.23	0.70
Married	-0.1	0.55	0.04	0.90	0.85
Employed pre-morbidly	-2.42	0.99	6.03	0.09	**0.01**
Welfare recipient	0.72	0.58	1.57	2.05	0.21
Experienced CSA	0.54	0.64	0.71	1.7	0.40
Experienced CPA	-1.71	0.75	5.19	0.18	**0.02**
Experienced ASPA	1.9	0.71	7.46	6.85	**0.007**
Carer to family	1.7	0.99	2.9	5.37	0.09
Patient has a carer	-0.72	0.53	1.8	0.49	0.18
Physical health diagnosis	-0.33	0.59	0.31	0.72	0.58
Health or social care worker	0.68	0.72	0.90	1.97	0.35
Uses a walking aid	1.7	0.54	9.63	5.3	**0.002**
Smoker	1.12	0.49	5.07	3.1	**0.02**

CSA: childhood sexual abuse; CPA: childhood physical abuse; ASPA: adulthood sexual or physical abuse

Table 102 Binary logistic regression showing associations between independent variables and FND membership after the removal of any patients with a schizophrenia diagnosis

Independent variables	B	SE	Wald	*p* value	OR
Female	0.53	0.62	0.73	0.39	1.7
British	0.004	0.50	0.001	0.99	1
Married	1.5	0.62	5.9	**0.02**	4.6
Employed pre-morbidly	0.89	0.74	1.43	0.23	2.4
Health or social worker	0.24	0.73	0.11	0.74	1.3
Smoker	-0.81	0.51	2.5	0.11	0.45
Psychiatric inpatient stay	-0.3	0.48	0.37	0.54	0.75
Physical health problem	2.47	0.72	11.85	**0.001**	11.8
Carer to family or friend	1.9	1.06	3.13	0.08	6.6
Has a carer	0.98	0.58	2.9	0.09	2.7
Abuse experience*	0.01	0.42	0.001	0.97	1.01

Model $\chi 2 = 46.9$, $p < 0.001$
Pseudo $R^2 = 0.34$
n = 807

Appendix 6.1: Reasons for early therapy cessation for F44.4 and control groups

Table 103 Reasons for early therapy cessation

	F44.4 Group n (%)	Control Group n (%)	χ^2	95% CI	*p* value
No reason available in notes	15 (44.1)	14 (63.6)	2	-9.7 – 45	0.16
Belief in a physical cause	5 (14.7)	0 (0)	3.5	-3.6 - 31	0.06
Belief therapy wasn't helping or was making patient worse	3 (8.8)	3 (3.9)	0.5	-14.4 – 20.2	0.48
Clinic too far to travel	3 (8.8)	0 (0)	0.5	-14.4 – 20.2	0.48
Symptoms improved	2 (5.9)	1 (4.5)	0.05	-17.6 – 15.9	0.82
Physical health problem (e.g. problem drinking or broken bone)	2 (5.9)	0 (0)	1.3	-10.4 – 19.7	0.25
Patient became too busy	1 (2.9)	1 (4.5)	0.1	-11.5 – 20.1	0.75
Disengaged from therapy	1 (2.9)	1 (4.5)	0.1	-11.5 – 20.1	0.75
Unhappy with service	1 (2.9)	0 (0)	0.64	-12.8 – 15.3	0.42
Found CBT distressing	1 (2.9)	1 (4.5)	0.1	-11.5 – 20.1	0.75
Police conviction	0 (0)	1 (4.5)	1.5	-6.7 – 22.8	0.22
Total	34 (100)	22 (100)			

Appendix 6.2: Missed treatment sessions and mean days between appointments

Table 104 Missed treatment sessions and mean number of days between appointments

	F44.4 Group mean (SD)	Control Group mean (SD)	Mann-Whitney U test	*p* value
Treatment sessions attended	14.06 (8)	13.4 (7.3)	3563.5	0.62
Treatment sessions missed	2.44 (4.2)	2.15 (3.8)	2449.5	0.66
Day between assessment and first treatment session	62.6 (74.6)	53.2 (46.9)	3090	0.69
Days between first and last treatment session	266 (362)	268 (408)	3341.5	0.51
Days between first treatment and last follow-up session	390.2 (277.7)	414.1 (297.7)	945.5	0.55

Appendix 6.3: Socio-demographic differences between F44.4 and control group patients according to their improvement

Table 105 Socio-demographic differences between patient groups who improved, got worse or remained the same after CBT treatment

		F44.4 Group n (%)	Control Group n (%)	χ^2	95% CI	*p* value
Patient improved		44 (49.4)	40 (58)	1.15	-7.9 – 24.6	0.28
Gender	Female	32 (72.7)	16 (40)	9	9.9 – 52.2	**0.003**
	Male	12 (27.3)	24 (60)			
Ethnicity	British	32 (72.7)	30 (75)	0.06	-18.1 – 22.1	0.81
	Other ethnicity	12 (27.3)	10 (25)			
Marital status	Single/divorced/widowed/ separated	24 (54.5)	23 (57.5)	0.08	-19.4 – 25	0.78
	Married/civil partner/cohabiting	20 (45.5)	17 (42.5)			
Work	Employed	20 (45.5)	21 (52.5)	0.41	-15.7 – 29	0.52
	Unemployed/retired/sick leave	24 (54.5)	19 (47.5)			
Benefits	Receives benefits	9 (22)	11 (31.4)	0.85	-12 – 30.6	0.36
	Does not receive benefits	32 (78)	24 (68.6)			
Age	Mean age at psychiatric symptom onset (SD)[1]	31.4 (16)	25.2 (13)	1.9	-0.38 – 12.8	0.07
	Mean age at assessment (SD)	40.6 (15)	39.8 (12)	0.28	-5.14 – 6.8	0.78
Role of psych	Accepted psych role before	26 (81.3)	-			
	Didn't accept psych role before	6 (18.8)	-			
Health	Experienced depression	38 (86.4)	33 (82.5)	0.24	-13.2 – 21.4	0.62
	Didn't experience depression	6 (13.6)	7 (17.5)			
	Smokes	11 (32.4)	13 (41.9)	0.62	-15.6 – 33.7	0.43
	Does not smoke	23 (67.6)	18 (58.1)			
	Family mental health problem	24 (66.7)	20 (64.5)	0.04	-21.8 – 26.4	0.85
	No family mental health issue	12 (33.3)	11 (35.5)			
Patient remained the same or got worse*		45 (50.6)	29 (42)	1.15	-7.9 – 24.6	0.28
Gender	Female	33 (73.3)	15 (51.7)	3.6	-2.7 – 44.3	0.06
	Male	12 (26.7)	14 (48.3)			
Ethnicity	British	28 (62.2)	21 (72.4)	0.81	-13.9 – 31.8	0.37
	Other ethnicity	17 (37.8)	8 (27.6)			
Marital status	Single/divorced/widowed/ separated	24 (53.3)	21 (72)	2.55	-6 – 40.2	0.11
	Married/civil partner/cohabiting	21 (46.7)	8 (27.6)			
Work	Employed	11 (25)	13 (44.8)	3.1	-4.14 – 42.6	0.08
	Unemployed/retired/sick leave	33 (75)	16 (55.2)			
Benefits	Receives benefits	24 (44.2)	11 (37.9)	0.28	-18.6 – 29.8	0.60
	Does not receive benefits	19 (55.8)	18 (62.1)			
Age	Mean age at psychiatric symptom onset (SD)[1]	29 (11)	32.9 (16)	-1.15	-10.7 – 2.9	0.26
	Mean age at assessment (SD)	39.5 (11)	42.8 (14)	-1.13	-9.1 – 2.5	0.26
Role of psych	Accepted psych role before	17 (48.6)	-			
	Didn't accept psych role before	18 (51.4)	-			
Health	Experienced depression	39 (86.7)	27 (93.1)	0.74	-11.5 – 21.2	0.39
	Didn't experience depression	6 (13.3)	2 (6.9)			
	Smokes	14 (43.8)	5 (26.3)	1.5	-12.9 – 42.8	0.21
	Does not smoke	18 (56.3)	14 (73.7)			
	Family mental health issue	22 (64.7)	16 (72.7)	0.39	-19.7 – 32.6	0.54
	No family mental health issue	12 (35.3)	6 (27.3)			
Not known		9 (9.2)	7 (9.2)			

*Eight F44.4 patients got worse and nine control patients got worse

[1] Independent samples *t*-test

Appendix 6.4: Socio-demographic differences between patients with clinical outcome scores and those with one or none

Table 106 Characteristics of FMD patients with two available CORE-OM scores versus those with one or no available CORE-OM scores

		CORE-OM scores available n (%)	No CORE-OM scores available n (%)	χ^2	95% CI	*p* value
Gender	Female	18 (75)	53 (71.6)	0.10	-20.5 – 22.6	0.74
	Male	6 (25)	21 (28.4)			
Ethnicity	British	16 (66.7)	50 (67.6)	0.007	-20.4 – 25.2	0.94
	Not British	8 (33.3)	24 (32.4)			
Marital status	Single	10 (47.6)	32 (61.5)	1.2	-12.9 – 39.4	0.28
	Married	11 (52.4)	20 (38.5)			
Work	Employed	11 (45.8)	22 (29.7)	2.1	-7.4 – 39.7	0.15
	Unemployed	13 (54.2)	51 (68.9)			
Carer	Patient has carer	6 (25)	18 (28.6)	0.11	-20.6 – 23.5	0.74
	Patient doesn't have carer	18 (75)	45 (71.4)			
Disability	Uses walking aid	8 (34.7)	36 (52.9)	2.3	-7.5 – 40.3	0.13
	No wheelchair/walking aid	15 (65.2)	32 (47.1)			
Abuse	History of CSA	2 (10)	17 (28.3)	2.7	-6 – 34.1	0.10
	No history of CSA	18 (90)	43 (71.7)			
	History of CPA	5 (25)	18 (24.3)	0.004	-20 – 26.8	0.95
	No history of CPA	15 (75)	43 (58.1)			
Health	History of familial mental health problems	15 (68.2)	36 (64.3)	0.11	-22.3 – 26.6	0.75
	No history of familial mental health problems	7 (31.8)	20 (35.7)			
	Smokes	7 (41.2)	23 (40.4)	0.003	-25.8 – 29.7	0.95
	Does not smoke	10 (58.8)	34 (59.6)			

Table 107 Characteristics of FMD patients with two available HoNOS-ABI scores versus those with one or no available scores

		HoNOS-ABI scores available n (%)	No HoNOS-ABI scores available n (%)	χ^2	95% CI	*p* value
Gender	Female	15 (68.2)	56 (73.7)	0.26	-15.7 – 30.4	0.61
	Male	7 (31.8)	20 (26.3)			
Ethnicity	British	12 (54.5)	54 (71.1)	2.1	-7.4 – 41	0.15
	Not British	10 (45.5)	22 (28.9)			
Marital status	Single	10 (52.6)	32 (50)	0.04	-24.4 – 28.8	0.84
	Married	9 (47.4)	32 (50)			
Work	Employed	9 (40.9)	24 (32)	0.59	-14.5 – 33.8	0.44
	Unemployed	13 (59.1)	51 (68)			
Carer	Patient has carer	8 (38.1)	16 (24.2)	1.5	-9.5 – 39.3	0.22
	Patient doesn't have carer	13 (61.9)	50 (75.8)			
Disability	Uses wheelchair or other walking aid	11 (55)	33 (46.5)	0.45	-8 – 33.5	0.50
	No wheelchair/walking aid	9 (45)	38 (53.5)			
Abuse	History of child sexual abuse	4 (23.5)	15 (23.8)	0.001	-27.8 – 21.1	0.98
	No history of child sexual abuse	13 (76.5)	48 (76.2)			
	History of child physical abuse	5 (29.4)	18 (28.1)	0.01	-21.6 – 29.9	0.91
	No history of child physical abuse	12 (70.6)	46 (71.9)			
Health	History of familial mental health problems	10 (55.6)	41 (68.3)	1.3	-10.2 – 35.6	0.25
	No history of familial mental health problems	8 (44.4)	19 (31.7)			
	Smokes	8 (50)	22 (37.9)	0.75	-16.7 – 40.3	0.34
	Does not smoke	8 (50)	36 (62.1)			

Table 108 Characteristics of FMD patients with two available PHQ-9 scores versus those with one or no available scores

		PHQ-9 scores available n (%)	No PHQ-9 scores available n (%)	χ^2	95% CI	*p* value
Gender	Female	14 (87.5)	57 (69.5)	2.2	-9.6 – 33.6	0.14
	Male	2 (12.5)	25 (30.5)			
Ethnicity	British	9 (56.3)	57 (69.5)	1.05	-13 – 41.3	0.31
	Not British	7 (43.8)	25 (30.5)			
Marital status	Single	10 (76.9)	32 (45.7)	4.2	-1.9 – 52.9	**0.04**
	Married	3 (23.1)	38 (54.3)			
Work	Employed	5 (31.3)	28 (34.6)	0.06	-26 – 26.5	0.80
	Unemployed	11 (68.8)	53 (65.4)			
Carer	Patient has carer	3 (21.4)	21 (28.8)	0.32	-23.6 – 27.9	0.57
	Patient doesn't have carer	11 (78.6)	52 (71.2)			
Disability	Uses wheelchair or other walking aid	8 (53.3)	36 (47.4)	0.17	-23.3 – 33.8	0.68
	No wheelchair/walking aid	7 (46.7)	40 (52.6)			
Abuse	History of child sexual abuse	1 (9.1)	18 (26.1)	2.1	-9.6 – 30.8	0.14
	No history of child sexual abuse	10 (90.1)	51 (73.9)			
	History of child physical abuse	3 (25)	20 (29)	0.1	-25 – 25	0.75
	No history of child physical abuse	9 (75)	49 (71)			
Health	History of familial mental health problems	8 (66.7)	43 (65.2)	0.01	-32.2 – 28.1	0.93
	No history of familial mental health problems	4 (33.3)	23 (34.8)			
	Smokes	4 (33.3)	26 (41.9)	0.39	-21.4 – 33.4	0.53
	Does not smoke	8 (66.7)	36 (58.1)			

Appendix 6.5: CORE-OM mean clinical score sub-analysis: repeated measures ANOVA

1. Gender

Female functional participants saw a significant decrease in mean CORE-OM scores before and after CBT (t = 3.5, df = 17, two-tailed p = 0.003) but there was no significant change in male participants' scores before and after treatment (t = 1.7, df = 5, two-tailed p = 0.14). The interaction between gender and the change over time within the F44.4 group was not statistically significant ($F_{1, 22}$ = 0.14, p = 72, partial η^2 = 0.006).

2. Ethnicity

British participants in the F44.4 group also saw a significant decrease in mean CORE-OM scores before and after CBT (t = 3.4, df = 15, two-tailed p = 0.004) while non-British participants did not see a significant drop in score results (t = 2, df = 7, two-tailed p = 0.08). The interaction between gender and the change over time within the F44.4 group was not statistically significant ($F_{1, 22}$ = 0.21, p = 66, partial η^2 = 0.009).

3. Marital Status

There was significant interaction in mean scores' change over time and marital status ($F_{1, 19}$ = 0.08, p = 0.77, partial η^2 = 0.004). Married participants saw a significant drop in CORE-OM scores post-CBT (t = 2.5, df = 10, two-tailed p = 0.03) compared to single participants, where there was no significant drop (t = 1.9, df = 9, two-tailed p = 0.10).

4. Employment

There was a significant interaction between CORE-OM clinical mean scores' change over time and employment status ($F_{1, 22}$ = 4.6, p = 0.04, partial η^2 = 0.17). Employed F44.4 participants saw a significant drop in their CORE-OM clinical mean scores (t = 3.7, df = 10, two-tailed p = 0.004) while there was no significant difference for unemployed participants (t = 2.1, df = 12, two-tailed p = 0.056).

5. Wheelchair usage

There were significant improvements in CORE-OM clinical mean scores for both wheelchair users/walking aid users (t = 2.8, df = 7, two-tailed p = 0.03) and non-wheelchair users (t = 2.5, df = 14, two-tailed p = 0.03) before and after CBT treatment but there was no significant interaction between the group and the two groups and the change in scores over time ($F_{1, 21}$ = 1.93, p = 0.18, partial η^2 = 0.08).

6. Acceptance of psychological factors before and after treatment

There was no significant interaction between those who accepted psychological factors before treatment and those who didn't and the change in their treatment scores over time ($F_{1, 15}$ = 0.004, p = 0.95, partial η^2 = 0.001). Those who accepted psychological factors displayed a significantly higher decrease in CORE-OM clinical mean scores (t = 3.1, df = 11, two-tailed p = 0.01) while those who did not accept psychological factors saw a drop in scores, but this wasn't statistically significant (t = 2.3, df = 4, two-tailed p = 0.09).

There was no significant interaction between those who accepted psychological factors after treatment and those who didn't accept such factors after treatment and time ($F_{1, 18}$ = 0.22, p = 0.64, partial η^2 = 0.01). There was a significant change in scores for those who accepted the role of psychology after CBT treatment (t = 3.2, df = 14, two-tailed p = 0.01) while there was no significant change for those who did not accept the role of psychological factors after CBT treatment.

7. Abuse

Participants who had experienced childhood physical abuse had no significant change in CORE-OM scores over time (t = 1.8, df = 4, p = 0.15) while those who did not experience childhood physical abuse saw a significant change over time (t = 3.4, df = 14, p = 0.004). The interaction between the childhood abuse variable and the change over time was not statistically significant ($F_{1, 18}$ = 0.46, p = 0.51, partial η^2 = 0.03).

There were less than five F44.4 participants who had experienced childhood sexual abuse or childhood physical abuse. Due to the small size of the groups, statistically tests were not completed for these groups.

8. Smoking

There was no significant change in scores over time within-groups for participants who smoked nor for those who did not smoke and the interaction between the two conditions (smokers and non-smokers) and the change over time was not significant ($F_{1, 15}$ = 2.5, p = 0.14, partial η^2 = 0.14).

9. Family mental health history

There was a significant decrease in CORE-OM scores for participants with family members with mental health problems before and after CBT (t =3, df = 14, p = 0.01), but not significant change in scores for participants with no family history of mental health problems (t = 2.4, df =

6, p = 0.06). There was no interaction between the groups and change in scores before and after CBT ($F_{1, 20}$ = 0.02, p = 0.89, partial η^2 = 0.001).

10. Carers

Participants without carers saw a significant drop in CORE-OM scores over time (t = 3.4, df = 17, p = 0.004) while there was no significant drop for those who did have a carer (t = 2.1, df = 5, p = 0.09). There was no significant interaction between groups and pre- and post-CBT CORE-OM scores ($F_{1, 22}$ = 0.28, p = 0.60, partial η^2 = 0.01).

Appendix 6.6: Mean adjusted HoNOS-ABI sub-analysis: repeated measures ANOVA

1. Gender

There was no significant interaction between gender and the change in HoNOS-ABI scores over time ($F_{1,}$ 20 = 0.97, p = 0.34, partial η^2 = 0.05) although females saw their HoNOS-ABI scores drop more than male participants.

2. Ethnicity

There was a significant interaction between ethnicity groups and the change in HoNOS-ABI scores over time ($F_{1,20}$ = 5.3, p = 0.03, partial η^2 = 0.21).

3. Marital Status

There was no significant interaction between marital status and the change over time in HoNOS-ABI scores ($F_{1, 17}$ = 1.02, p = 0.22, partial η^2 = 0.06).

4. Employment status

There was no significant interaction between employment status and change over time in HoNOS-ABI scores ($F_{1, 20}$ = 0.05, p = 0.83, partial η^2 = 0.002).

5. Psychological acceptance before and after CBT

There was no interaction effect between those accepting psychological factors before CBT and those not accepting psychological factors before CBT and change in HoNOS-ABI scores over time ($F_{1, 13}$ = 0.53, p = 0.48, partial η^2 = 0.04).

There was no interaction effect between those accepting psychological factors after CBT and those not accepting psychological factors after CBT and change in HoNOS-ABI scores over time ($F_{1, 16}$ = 2.5, p = 0.13, partial η^2 = 0.14).

6. Carers

There was no significant interaction by carer group (has a carer versus has no carer) and the change in HoNOS-ABI scores over time ($F_{1,19}$ = 0.92, p = 0.35, partial η^2 = 0.05).

7. Abuse

There was no significant interaction between experiencing childhood physical abuse or not and the change in HoNOS-ABI scores over time ($F_{1,15}$ = 1.4, p = 0.25, partial η^2 = 0.09).

Repeated measures ANOVA was not completed for those experiencing childhood sexual abuse and those not as the number of those experiencing childhood sexual abuse was below the pre-agreed cut-off of five participants per group (n = 4). The same principle applied to comparisons of those experiencing adult sexual or physical abuse (n = 1).

8. Wheelchair usage

There was no interaction effect for wheelchair usage and change over time in HoNOS-ABI scores ($F_{1,18} = 2.3$, $p = 0.15$, partial $\eta^2 = 0.11$).

9. Family mental health

There was no interaction effect for those with family members with mental health problems or without and change in HoNOS-ABI scores over time ($F_{1,16} = 0.05$, $p = 0.82$, partial $\eta^2 = 0.003$).

10. Smoking

There was no significant interaction for smoking group and change in HoNOS-ABI scores pre- and post-CBT ($F_{1,14} = 0.38$, $p = 0.55$, partial $\eta^2 = 0.03$).

Appendix 6.7: Mean PHQ-9 scores sub-analyses: repeated measures ANOVA

1. Gender

There was no interaction between gender and the change over time in PHQ-9 mean scores ($F_{1, 14}$ = 0.17, p = 0.68, partial η^2 = 0.01). The total number of men with available scores at both time points was however only two.

2. Ethnicity

There was no significant interaction for ethnicity and change in PHQ-9 scores over time ($F_{1,14}$ = 2.3, p = 0.15, partial η^2 = 0.14).

3. Marital status

There was no significant interaction between marital status and PHQ-9 scores over time ($F_{1, 11}$ = 0.41, p = 0.53, partial η^2 = 0.04). There were only three married F44.4 participants with PHQ-9 scores at both time points.

4. Employment

There was no interaction between employment status (unemployed n = 11, employed n = 5) and change in PHQ-9 scores over time ($F_{1,14}$ = 0.57, p = 0.46, partial η^2 = 0.04).

5. Psychological acceptance before and after CBT

There were only two F44.4 participants who did not accept psychological factors as part of their symptomatology. Nine participants did accept these factors. There was no interaction between this variable and change in scores over time ($F_{1, 9}$ = 1.08, p = 0.33, partial η^2 = 0.11).

In relation to patients who did and did not accept the role of psychology in their symptoms after CBT, only one participant did not accept the role it plays. The interaction between the group accepting or not accepting psychological factors after CBT and the change in PHQ-9 scores over time was not significant ($F_{1,13}$ = 0.99, p = 0.34, partial η^2 = 0.07).

6. Carer

Only three patients with before and after CBT PHQ-9 scores reported having a carer. There was no significant interaction between having a carer or not and change over time in PHQ-9 scores ($F_{1,12}$ = 0.12, p = 0.74, partial η^2 = 0.01).

7. Abuse

Three participants with before and after CBT PHQ-9 scores reported experiencing childhood physical abuse. There was no interaction effect for these groups over time ($F_{1,10}$ = 0.02, p = 0.89, partial η^2 = 0.002).

In total, four participants reported experiencing sexual or physical abuse as an adult. No interaction effect was reported ($F_{1,12}$ = 1.71, p = 0.22, partial η^2 = 0.13).

Regarding childhood sexual abuse, only one participant experienced childhood sexual abuse with two PHQ-9 scores and no analysis was completed.

8. Wheelchair use

There was no interaction for those F44.4 patients using wheelchairs or walking aids and those not and the change in their PHQ-9 scores over time ($F_{1,13}$ = 0.15, p = 0.71, partial η^2 = 0.01).

9. Family mental health

Only four participants had no family members with mental health problems and two PHQ-0 scores while eight did. Those with family members with mental health problems saw a greater decrease in PHQ-9 scores than those participants without a family member with a mental health problem, though the interaction was not significant ($F_{1,10}$ = 3.3, p = 0.10, partial η^2 = 0.25).

10. Smoking

Four participants had two complete PHQ-9 scores and smoked. There was no significant interaction between smoking status and change in PHQ-9 scores over time ($F_{1,10}$ = 1.9, p = 0.20, partial η^2 = 0.16).